Nationale Krebsregistrierungsstelle
Organe national d'enregistrement du cancer
Servizio nazionale di registrazione dei tumori
National Agency for Cancer Registration

Kinderkrebsregister
Registre du cancer de l'enfant
Registro dei tumori pediatrici
Childhood Cancer Registry

NATIONAL CANCER DATA DICTIONARY

V 1.3

Part A

BASIC VARIABLES

for

Adults, Adolescents, and Children

01.01.2024

IMPRINT

Publisher	National Agency for Cancer Registration (NACR)
	Childhood Cancer Registry (ChCR)
Information	National Agency for Cancer Registration (NACR), Tel. 044 634 53 74, E-Mail: info@nkrs.ch
Projectleaders	Simone Bader, Federal Office of Public Health (FOPH)
	Claudia Kuehni, ChCR
	Verena Pfeiffer, ChCR
	Ulrich Wagner, NACR/NICER
Authors	Matthias Lorez, NACR/NICER
	Regina Nanieva, NACR/NICER
	Shelagh Redmond, ChCR / Federal Office of Public Health (FOPH)
	Martin Stierlin, Cancer registry Bern Solothurn / Federal Office of Public Health (FOPH)
	Katharina Staehelin, NACR/NICER (from version 1.3)
	Greta Eggebrecht, NACR/NICER (from version 1.3)

Contributors Martin Adam, Foundation Cancer registry Aargau. Emin Aghayev, Federal Office of Public Health (FOPH). Andrea Bordoni, Registro cantonale dei tumori. Markus Borner, Spitalzentrum Biel. Christoph Bosshard, Berufsverband der Schweizer Ärztinnen und Ärzte (FMH). Peter Brauchli, Schweizerische Arbeitsgemeinschaft für Klinische Krebsforschung (SAKK). Gieri Cathomas, Kantonsspital Baselland. Ivan Curjuric, Foundation Cancer registry Aargau. Catherine Gasser, Schweizer Krebsliga (KLS) / Nationale Strategie gegen Krebs (NSK). Philippe Groux, Nationale Strategie gegen Krebs (NSK). Rolf Heusser, NICER. Felicitas Hitz, Kantonsspital St. Gallen / Schweizerische Gesellschaft für Medizinische Onkologie (SGMO). Esther Kraft, Berufsverband der Schweizer Ärztinnen und Ärzte (FMH). Franziska Lenz, Schweizer Krebsliga (KLS). Rolf Marti, Schweizer Krebsliga (KLS). Manuela Maspoli, Registres neuchâtelois et jurassien des tumeurs. Kilian Moser, Federal Office of Public Health (FOPH). Mohsen Mousavi, Cancer registry Ostschweiz / Cancer registry of the cantons Graubünden and Glarus. Isabelle Neyroud, Registre genevois des tumeurs. Michael Roethlisberger, Schweizer Krebsliga (KLS) / Nationale Strategie gegen Krebs (NKS). Sabine Rohrmann, Cancer registry of the cantons Zürich / Zug / Schwyz / Schaffhausen / Institut für Epidemiologie, Biostatistik und Prävention. Annelies Schnider, Stadtspital Triemli Zürich. Nicolas von der Weid, Universitäts-Kinderspital beider Basel (UKBB) / Schweizerische Pädiatrische Onkologie Gruppe (SPOG). Roger von Moos, Kantonsspital Graubünden / Schweizerische Arbeitsgemeinschaft für Klinische Krebsforschung (SAKK). Kathrin Zaugg, Stadtspital Triemli Zürich.

Link	https://www.nacr.ch/
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CONTENTS

Note: Variables labelled with a star (*****) will not be submitted to the NACR.

Changes made between versions 1.2 and 1.3 are indicated by a grey background. All changes are listed in the appendix.

ABBREVIATIONS

AHV	Alters- und Hinterlassenenversicherung
AIDS	Acquired immunodeficiency syndrome
AJCC	American Joint Committee on Cancer
AVS	Assurance vieillesse et survivants
BFS	Bundesamt für Statistik
CBC	Complete blood count
CHOP	Swiss Classification for Treatment Procedures
COG	Children's Oncology Group
CRM	Circumferential resection margins
CSF	Cerebrospinal fluid
DCO	Death Certificate Only
DSSplus	Durie-Salmon Plus staging system
EBV	Epstein Barr virus
ENCR	European Network of Cancer Registries
FDFA	Federal Department of Foreign Affairs
FIGO	International Federation of Gynecology and Obstetrics
FSO	Federal Statistical Office
hCG	Human chorionic gonadotropin
HPV	Human papillomavirus
IACR	International Association of Cancer Registries
IARC	International Agency for Research on Cancer – World Health Organization
ICCC	International Classification of Childhood Cancer
ICD	International Classification of Diseases
ICD-O	International Classification of Diseases for Oncology
INRGSS	International Neuroblastoma Risk Group Staging System
IRSS	International Retinoblastoma Staging System
ISS	International Staging System;
LDH	Lactate dehydrogenase
NACR	National Agency for Cancer Registration
NICER	National Institute for Cancer Epidemiology and Registration
OASI	Old-Age and Survivors' Insurance number
PET/CT	Positron emission tomography and computed tomography
PRETEXT	PRE-Treatment EXTent of tumor
PSA	Prostate Specific Antigen
R-ISS	Revised International Staging System
SIOP	International Society of Pediatric Oncology
SIOPEL	International Childhood Liver Tumor Strategy Group
SPECT	Single photon emission computed tomography
TNM	Classification of Malignant Tumours
UICC	Union for International Cancer Control
WHO	World Health Organization

CASE DEFINITIONS

Person age at diagnosis

Children (0-14.99 years), Adolescents (15-19.99 years), and Adults (20 and more years).

Person resident status[1]

The person diagnosed is part of the permanent resident population (i.e. the dominator for calculation of event rates):

>Swiss citizens with main place of residency in Switzerland.

>Foreign citizens with an annual or a permanent residence permit for at least twelve months (Permit B or C or FDFA-ID[2] [international civil servants, diplomats and their family members]).

>Foreign citizens with a short-term residence permit (Permit L) for a cumulative length of stay of at least twelve months.

>Foreign citizens seeking asylum (Permit F or N) with a total length of stay of at least twelve months.

No veto from patient

The Cantonal Cancer Registries and the Childhood Cancer Registry may register incoming data on a patient for whom they have not previously registered data, provided that the patient has not objected within three months of receipt of the first notification of cancer.

Reportable diagnosed neoplasms[3]

ICD-10

All malignant neoplasms	C00 – C97	[except Basaliomas (C44: 8090-8098)]
All carcinoma in-situ	D00 – D09	[except D04 «Carcinoma in situ of skin»]
Benign neoplasms	D32	(Meninges)
	D33	(Brain and other parts of central nervous system)
	D35	(Other and unspecified endocrine glands) [except adults]
	D35.2	[except hormone-inactive pituitary microadenomas (< 10 mm)]
All Neoplasms of uncertain or unknown behaviour	D37 – D48	[except Monoclonal gammopathy D47.2]
	D61	(Other aplastic anaemias) [except in Adults]
	D76	(Certain diseases involving lymphoreticular tissue and reticulohistiocytic system) [except in Adults]

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[1] Ordinance 431.112.1 (19.12.2008) on the Federal Population Census, Article 2 Letter d.

[2] International civil servants, diplomats and their family members with undefined regional responsibility of the registry are excluded.

[3] Only verified diagnoses are reportable. Verification refers to medically accepted diagnostic procedures (clinical, cytological, histological, laboratory test).

PATIENT DATA

1.1.1   Family Name(s)*

Variable number: **1.1.1**
      Item length: 255
      Item format: Text

Definition

The data item records the family name (last name or surname) at the time of diagnosis.

Rationale

The information serves as personal identifier.

Code examples[#]
Müller
Müller-Rochat
Müller Rochat
…

#: only examples are shown to reduce table size

National usage

(*) The variable is not to be submitted to the NACR.

References

-

Notes

>More than a single family name may optionally be registered per person (i.e. the person's family name history at different times, or name variants/spellings at the same time).

>If the patient has more than a single reportable diagnosis, the family name at diagnosis may be different in each case.

1.1.2   First Name(s)*

Variable number: **1.1.2**
       Item length: 255
       Item format: Text

Definition
The data item records the first name at the time of diagnosis. One or more names may be recorded.

Rationale
The data item is used to differentiate between persons with the same last name.

Code examples[#]
Daniel
Daniel Peter
Maria A. Ursula
…

#: only examples are shown to reduce table size

National usage
(*****) The variable is not to be submitted to the NACR.

References

-

Notes
>Official as well as inofficial (chosen) first names, i.e. the person's first name history at different times, or name variants/spellings at the same time, may optionally be registered to facilitate identification.
>If the patient has more than a single reportable diagnosis, the first name at diagnosis may be different in each case.

1.2   Sex

Variable number: **1.2**

      Item length: 1

      Item format: Number

Definition

The data item records the person's sex at the time of diagnosis.

Rationale

The information is used to compare cancer rates and outcomes by sex.

Code	Label
1	Male
2	Female
3	Other (e.g. hermaphrodite; transsexual, born male; transsexual, born female; biological sex not same as self-assigned sex; genetic sex differs from sex assigned at birth; etc.)
9	Unknown (not stated in records)

National usage

The variable is to be submitted to the NACR.

References

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Notes

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1.3.1   Date of Birth

Variable number: **1.3.1**

     Item length: 10

     Item format: Date (dd.mm.yyyy)

Definition

The data item records the date of birth.

Rationale

The information is used for person identification and to compare cancer rates and outcomes by birth cohort.

Code examples[#]	Description
01.01.2005	Note: for single digit day or month, record with a leading 0.
15.01.2005	Note: if exact day unknown, set day as 15th of the respective month.
30.06.2005	Note: if exact day and month unknown, set date as 30th of June of the respective year.
…	

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR in truncated form, with day set to unknown (i.e. 15) for all cases.

References

-

Notes

-

1.3.2 Accuracy for date of birth

Variable number: **1.3.2**

Item length: 1

Item format: Number

Definition

The data item indicates the accuracy of the date of birth.

Rationale

The information is used to identify case groups where age or time period is not known with certainty (e.g. for sensitivity analyses).

Code	Label	Description
0	Exact date	All date components are known.
1	Day uncertain	The day in date is imputed.
2	Day/Month uncertain	The day and month in date are imputed.
3	Estimated date	All date components are imputed.

National usage

The variable is to be submitted to the NACR.

References

-

Notes

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1.4 OASI number*

Variable number: **1.4**
Item length: 13
Item format: Text

Definition
The official 13-digit unique person identification number: OASI (Old-Age and Survivors' Insurance).

Rationale
The data item is used to uniquely identify the person.

Code structure	X_{n-12} X_{n-11} X_{n-10}	X_{n-9} X_{n-8} X_{n-7} X_{n-6} X_{n-5} X_{n-4} X_{n-3} X_{n-2} X_{n-1}	X_n
Description	Country	Person	Control number

National usage
(*****) The variable is not to be submitted to the NACR. The NACR will use a pseudonymized number only.

References
>Artikel 50c des Bundesgesetzes vom 20. Dezember 1946 (SR 831.10) über die Alters- und Hinterlassenenversicherung.

Notes
>OASI in German/French, Italian: AHV/AVS.

1.5.1   Street name*

Variable number: **1.5.1**
    Item length: 255
    Item format: Text

Definition
The data item records the street name of the address at the time of diagnosis.

Rationale
Address information indicates referral patterns and allows for the analysis of cancer clusters or environmental studies.

Code examples[#]
Bahnhofstrasse
…

#: only examples are shown to reduce table size

National usage
(*****) The variable is not to be submitted to the NACR.

References
-

Notes
>If more than a single diagnosis is registered per person, the address may be different for each case.
>Additional addresses at other points in time may optionally be recorded to facilitate the matching of new information to persons already registered.
>Addresses may be specified as a history including arrival, moving and last validated date of residence.

1.5.2   Street number*

Variable number: **1.5.2**

       Item length: 10

       Item format: Alphanumeric

Definition

The data item records the street number of the address at the time of diagnosis.

Rationale

Address information indicates referral patterns and allows for the analysis of cancer clusters or environmental studies.

Code examples[#]
10a
…

#: only examples are shown to reduce table size

National usage

(*) The variable is not to be submitted to the NACR.

References

-

Notes

>If more than a single diagnosis is registered per person, the address may be different for each case.

>Additional addresses at other points in time may optionally be recorded to facilitate the matching of new information to persons already registered.

>Addresses may be specified as a history including arrival, moving and last validated date of residence.

1.5.3   Extra address line*

Variable number: **1.5.3**

        Item length: 255

        Item format: Text

Definition

The data item records additional lines of the patient's address at the time of diagnosis.

Rationale

Address information indicates referral patterns and allows for the analysis of cancer clusters or environmental studies.

Code examples[#]
Postlagernd
…

#: only examples are shown to reduce table size

National usage

(*****) The variable is not to be submitted to the NACR.

References

-

Notes

>If more than a single diagnosis is registered per person, the address may be different for each case.

>Additional addresses at other points in time may optionally be recorded to facilitate the matching of new information to persons already registered.

>Addresses may be specified as a history including arrival, moving and last validated date of residence.

1.6   Postcode*

Variable number: **1.6**

      Item length: 4

      Item format: Number

Definition

The data item records the four-digit postcode of the address at the time of diagnosis.

Rationale

Address information indicates referral patterns and allows for the analysis of cancer clusters or environmental studies.

Code examples#	Description
1000	Situated in Lausanne
1003	Situated in Lausanne
1004	Situated in Lausanne
1005	Situated in Lausanne
1006	Situated in Lausanne
1007	Situated in Lausanne
1008	Situated in Jouxtens-Mézery
…	…
9657	Situated in Wildhaus-Alt St. Johann
9658	Situated in Gams
9658	Situated in Grabs
9658	Situated in Wildhaus-Alt St. Johann

#: only examples are shown to reduce table size

National usage

(*****) The variable is not to be submitted to the NACR.

References

>www.bfs.admin.ch/bfsstatic/dam/assets/4242620/master [last access: 27.11.2018]

Notes

>If more than a single diagnosis is registered per person, the address may be different for each case.

>Additional addresses at other points in time may optionally be recorded to facilitate the matching of new information to persons already registered.

>Addresses may be specified as a history including arrival, moving and last validated date of residence.

1.7   City/Municipality name*

Variable number: **1.7**
  Item length: 255
  Item format: Text

Definition

The data item records the FSO City/Municipality name of the address at the time of diagnosis.

Rationale

Address information indicates referral patterns and allows for the analysis of cancer clusters or environmental studies.

Code examples#
Aeugst am Albis
Affoltern am Albis
Bonstetten
Hausen am Albis
…

#: only examples are shown to reduce table size

National usage

(*****) The variable is not to be submitted to the NACR.

References

>www.bfs.admin.ch/bfsstatic/dam/assets/4242620/master [last access: 27.11.2018]

Notes

>If more than a single diagnosis is registered per person, the address may be different for each case.
>Additional addresses at other points in time may optionally be recorded to facilitate the matching of new information to persons already registered.
>Addresses may be specified as a history including arrival, moving and last validated date of residence.

1.8   Canton number

Variable number: **1.8**

         Item length: 2

         Item format: Number

Definition

The data item records the FSO canton number of the address at the time of diagnosis.

Rationale

Address information indicates referral patterns and allows for the analysis of cancer clusters or environmental studies.

Code examples[#]	Label	Description
1	ZH	Zürich
2	BE	Bern / Berne
…	…	
25	GE	Genève
26	JU	Jura

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>FSO: www.bfs.admin.ch/bfs/de/home/grundlagen/raumgliederungen [last access: 4.2.19]

Notes

>If more than a single diagnosis is registered per person, the address may be different for each case.

>Additional addresses at other points in time may optionally be recorded to facilitate the matching of new information to persons already registered.

>Addresses may be specified as a history including arrival, moving and last validated date of residence.

1.9   FSO City/Municipality number

Variable number: **1.9**

       Item length: 4

       Item format: Number

Definition

The data item records the FSO city/Municipality number of the address at the time of diagnosis.

Rationale

Address information indicates referral patterns and allows for the analysis of cancer clusters or environmental studies.

Code examples[#]	Label
1	Aeugst am Albis
2	Affoltern am Albis
…	…
6809	Haute-Ajoie
6810	La Baroche

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>https://www.cadastre.ch/de/services/service/registry/plz.html

Note

>If more than a single diagnosis is registered per person, the address may be different for each case.

>Additional addresses at other points in time may optionally be recorded to facilitate the matching of new information to persons already registered.

>Addresses may be specified as a history including arrival, moving and last validated date of residence.

1.10   Place of birth

Variable number: **1.10**

       Item length: 4

       Item format: Number

Definition

The date item records the FSO city/municipality number of the place of birth if the person was born in Switzerland, or the FSO country number of the place of birth, if the country of birth is not Switzerland, or if the birthplace in Switzerland is not stated.

Rationale

This data item is used to evaluate medical care delivery to special populations and to identify populations at special risk for certain cancers.

Code examples#	Label	Description
1	Aeugst am Albis	FSO city number (born in CH)
2	Affoltern am Albis	FSO city number (born in CH)
…	…	FSO city number (born in CH)
6809	Haute-Ajoie	FSO city number (born in CH)
6810	La Baroche	FSO city number (born in CH)
8100	Switzerland	FSO country code (born in CH), unspecified
8201	Albania	FSO country code (not born in CH)
…	…	FSO country code (not born in CH)
8703	French Southern and Antarctic Lands	FSO country code (not born in CH)
9999	Unknown (not stated in patient record)	FSO country code (not born in CH)

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

> https://www.bfs.admin.ch/bfs/en/home/basics/swiss-official-commune-register.html [last access: 18.09.2023]
> https://www.bfs.admin.ch/bfs/de/home/grundlagen/stgb.assetdetail.22870013.html [last access: 18.09.2023]

Notes

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1.11   Nationality

Variable number: **1.11**

Item length: 4

Item format: Number

Definition

The data item records the FSO country number of the person's nationality at time of diagnosis.

Rationale

This data item is used to evaluate medical care delivery to special populations and to identify populations at special risk for certain cancers.

Code examples[#]	Label
8100	Switzerland
8201	Albania
8202	Andorra
…	…
8701	Antarctica
8702	Bouvet Island
8703	French Southern and Antarctic Lands
9999	Unknown (not stated in patient record)

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

> https://www.fedlex.admin.ch/eli/cc/2006/619/en [last access: 20.09.2023]

Notes

>If more than a single diagnosis is registered per person, the nationality may be different for each case.

1.12   Civil status

Variable number: **1.12**

      Item length: 1

      Item format: Number

Definition

The data item records the civil status at the time of diagnosis using FSO Population and Households Statistics categories.

Rationale

Studies have shown that the civil status has significant impacts on the survival of various cancers. Civil status facilitates data linkage to the official Swiss Vital Statistics.

Code	Label	Description
1	Never Married	
2	Married	
3	Widowed	
4	Divorced	
5	Annulled marriage*	"Anulled marriage" can arise because the last marriage has been declared invalid or because the last spouse has been declared a missing person.
6	Registered partnership	
7	Dissolved partnership	
9	Unknown	Not stated / Not assessed.

* German: "Unverheiratet"; French: "Non marié"; Italian: "Non coniugati"

National usage

The variable is to be submitted to the NACR.

References

>Amtlicher Katalog der Merkmale. Bundesamt für Statistik (BFS). Neuchâtel, 2014. ISBN: 978-3-303-00504-0.
>www.bfs.admin.ch/bfs/de/home/statistiken/bevoelkerung/erhebungen/statpop [last access: 13.5.2019]

Notes

>If more than a single diagnosis is registered per person, the civil status may be different for each case.

1.13   Vital status

Variable number: **1.13**

         Item length: 1

         Item format: Number

Definition

The data item records the vital status at the date of reference.

Rationale

Essential information for prevalence statistics and survival studies.

Code	Label	Description
1	Alive	Person is alive at vital status update.
2	Dead	Person is dead.
3	Lost to follow-up	No further information about the vital status when updating the vital status. Date of reference is the last date when the person was known to be alive.
9	Unknown	Vital status could not be traced by any type of update procedure.

National usage

The variable is to be submitted to the NACR.

References

-

Notes

>Vital status must be updated on a regular basis, at least annually.

1.14.1   Date for vital status

Variable number: **1.14.1**

    Item length: 10

    Item format: Date (dd.mm.yyyy)

Definition

The data item records the date of last vital status update or the date of death.

Rationale

The information is required for prevalence statistics and survival time analyses.

Code examples[#]	Description
01.01.2005	Note: for single digit day or month, record with a leading 0.
15.01.2005	Note: if exact day unknown, set day as 15th of the respective month.
30.06.2005	Note: if exact day and month unknown, set date as 30th of June of the respective year.
…	

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR in truncated form, with day set to unknown (i.e. 15) for all cases. In addition, the accompanying age in days will be submitted to the NACR.

References

-

Notes

>Vital status must be updated on a regular basis, at least annually.

1.14.2   Accuracy for date of vital status

Variable number: **1.14.2**

         Item length: 1

         Item format: Number

Definition

Indicates the accuracy of the date of reference for the given vital status of the patient.

Rationale

The data item is used to identify groups of patients where ages or time periods are not known with certainty (e.g. for sensitivity analyses).

Code	Label	Description
0	Exact date	All date components are known.
1	Day uncertain	The day in date is imputed.
2	Day/Month uncertain	The day and month in date are imputed.
3	Estimated date	All date components are imputed.

National usage

The variable is to be submitted to the NACR.

References

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Notes

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1.15   Cause of death (registry-based)*

Variable number: **1.15**

       Item length: 5

       Item format: Alphanumeric

Definition

The data item indicates the International Classification of Diseases (ICD) code for the primary cause of death, according to the cancer registry. To code with three digits is sufficient (exception see Notes). To code only cases with cancer as cause of death is sufficient. The item is entered without decimal point.

Rationale

The cancer registry may have more accurate information on the cause of death than is provided on the death certificate. It opens the possibility to collaborate with the FSO in correcting the official vital statistics.

Code examples#	Label
B17	Other acute viral hepatitis
B24	Unspecified human immunodeficiency virus [HIV] disease
C342	Malignant neoplasm of middle lobe, bronchus or lung.
…	…
Z99	Dependence on enabling machines and devices, not elsewhere classified

#: only examples are shown to reduce table size

National usage

(*****) The variable is not to be submitted to the NACR.

References

>ICD: https://icd.who.int/browse10/2016/en [last accessed: 30.3.2022].

Notes

>Mesothelioma of pleura (C450) and malignant neoplasm of pleura (C384) must be recorded with four digits.

1.16 Principal cause of death

Variable number: **1.16**

    Item length: 5

    Item format: Alphanumeric

Definition

The data item records the International Classification of Diseases (ICD) principal cause of death according to Swiss Federal Statistical Office (FSO). This is the underlying disease that caused all other ailments within a logical chain and is considered as the mono-causal cause of death. The official name in German is "endgültige Todesursache", and in French "la cause finale de décès", and in Italian "causa finale di morte". The data item is entered without decimal point.

Rationale

The principal cause of death, determined from cause of death certificate information using international guidelines, forms the basis of the official cancer mortality statistics.

Code examples[#]	Label
A000	Cholera due to Vibrio cholerae 01, biovar cholerae
A001	Cholera due to Vibrio cholerae 01, biovar el tor
…	…
Z998	Dependence on other enabling machines and devices
Z999	Dependence on unspecified enabling machine and device

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

> https://icd.who.int/browse10/2016/en [last accessed: 27.12.2018].

>Richtlinien für die ärztliche Bescheinigung der Todesursachen. Bundesamt für Statistik (BFS). Reihe: Statistik der Schweiz. Fachbereich: 14 Gesundheit. Bern 1996. ISBN: 3-303-14025-1.

>Richtlinien zur Kodierung der Todesursachen nach der ICD-10-Klassifikation. Bundesamt für Statistik (BFS). Stand der Überarbeitung: 5.7.2011.

Notes

>It is required that the official vital statistics issued annually by the FSO is linked to the registry dataset.

1.17.1   Underlying cause of death

Variable number: **1.17.1**

       Item length: 5

       Item format: Alphanumeric

Definition

The data item records the International Classification of Diseases (ICD) primary cause of death from the cause of death certificate according to Swiss Federal Office of Statistics. The official name in German is "Grundkrankheit, Grundursache", and in French "Maladie initiale, cause primaire", and in Italian "Malattia iniziale, causa primaria". The item is entered without decimal point.

Rationale

This information is required to identify missed cancer diagnoses. It is also used to estimate the number of existing cancer diagnoses that were not captured by registration.

Code examples[#]	Label
A000	Cholera due to Vibrio cholerae 01, biovar cholerae
A001	Cholera due to Vibrio cholerae 01, biovar el tor
…	…
Z998	Dependence on other enabling machines and devices
Z999	Dependence on unspecified enabling machine and device

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>https://icd.who.int/browse10/2016/en [last accessed: 27.12.2018].

>Richtlinien für die ärztliche Bescheinigung der Todesursachen. Bundesamt für Statistik (BFS). Reihe: Statistik der Schweiz. Fachbereich: 14 Gesundheit. Bern 1996. ISBN: 3-303-14025-1.

>Richtlinien zur Kodierung der Todesursachen nach der ICD-10-Klassifikation. Bundesamt für Statistik (BFS). Stand der Überarbeitung: 5.7.2011.

Notes

>It is required that the official vital statistics issued annually by the FSO is linked to the registry dataset.

1.17.2   Intermediate cause of death

Variable number: **1.17.2**

           Item length: 5

           Item format: Alphanumeric

Definition

The data item records the International Classification of Diseases (ICD) secondary cause of death from the cause of death certificate according to Swiss Federal Office of Statistics. The official name in German is "Folgekrankheit, unmittelbare Ursache des Todesfalles", and in French "Maladie secondaire, cause directe du décès", and in Italian "Malattia secondaria, causa di morte diretta". The item is entered without decimal point.

Rationale

This information is required to identify missed cancer diagnoses. It is also used to estimate the number of existing cancer diagnoses that were not captured by registration.

Code examples[#]	Label
A000	Cholera due to Vibrio cholerae 01, biovar cholerae
A001	Cholera due to Vibrio cholerae 01, biovar el tor
…	…
Z998	Dependence on other enabling machines and devices
Z999	Dependence on unspecified enabling machine and device

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>https://icd.who.int/browse10/2016/en [last accessed: 27.12.2018].

>Richtlinien für die ärztliche Bescheinigung der Todesursachen. Bundesamt für Statistik (BFS). Reihe: Statistik der Schweiz. Fachbereich: 14 Gesundheit. Bern 1996. ISBN: 3-303-14025-1.

>Richtlinien zur Kodierung der Todesursachen nach der ICD-10-Klassifikation. Bundesamt für Statistik (BFS). Stand der Überarbeitung: 5.7.2011.

Notes

>It is required that the official cause of death statistics issued annually by the FSO is linked to the registry dataset.

1.17.3   First concomitant cause of death

Variable number: **1.17.3**

         Item length: 5

         Item format: Alphanumeric

Definition

The data item records the International Classification of Diseases (ICD) first tertiary cause of death from the cause of death certificate according to Swiss Federal Office of Statistics. The official name in German is "Begleitkrankheiten", and in French "Maladie concomitantes", and in Italian "Malattie concomitanti". The item is entered without decimal point.

Rationale

This information is required to identify missed cancer diagnoses. It is also used to estimate the number of existing cancer diagnoses that were not captured by registration.

Code examples[#]	Label
A000	Cholera due to Vibrio cholerae 01, biovar cholerae
A001	Cholera due to Vibrio cholerae 01, biovar el tor
…	…
Z998	Dependence on other enabling machines and devices
Z999	Dependence on unspecified enabling machine and device

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>https://icd.who.int/browse10/2016/en [last accessed: 27.12.2018].

>Richtlinien für die ärztliche Bescheinigung der Todesursachen. Bundesamt für Statistik (BFS). Reihe: Statistik der Schweiz. Fachbereich: 14 Gesundheit. Bern 1996. ISBN: 3-303-14025-1.

>Richtlinien zur Kodierung der Todesursachen nach der ICD-10-Klassifikation. Bundesamt für Statistik (BFS). Stand der Überarbeitung: 5.7.2011.

Notes

>It is required that the official vital statistics issued annually by the FSO is linked to the registry dataset.

1.17.4   Second concomitant cause of death

Variable number: **1.17.4**

    Item length: 5

    Item format: Alphanumeric

Definition

The data item records the International Classification of Diseases (ICD) second tertiary cause of death from the cause of death certificate according to Swiss Federal Office of Statistics. The official name in German is "Begleitkrankheiten", and in French "Maladie concomitantes", and in Italian "Malattie concomitanti". The item is entered without decimal point.

Rationale

This information is required to identify missed cancer diagnoses. It is also used to estimate the number of existing cancer diagnoses that were not captured by registration.

Code examples#	Label
A000	Cholera due to Vibrio cholerae 01, biovar cholerae
A001	Cholera due to Vibrio cholerae 01, biovar el tor
…	…
Z998	Dependence on other enabling machines and devices
Z999	Dependence on unspecified enabling machine and device

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>https://icd.who.int/browse10/2016/en [last accessed: 27.12.2018].

>Richtlinien für die ärztliche Bescheinigung der Todesursachen. Bundesamt für Statistik (BFS). Reihe: Statistik der Schweiz. Fachbereich: 14 Gesundheit. Bern 1996. ISBN: 3-303-14025-1.

>Richtlinien zur Kodierung der Todesursachen nach der ICD-10-Klassifikation. Bundesamt für Statistik (BFS). Stand der Überarbeitung: 5.7.2011.

Notes

>It is required that the official vital statistics issued annually by the FSO is linked to the registry dataset.

1.18   ICD-version for causes of death

Variable number: **1.18**

        Item length: 2

        Item format: Number

Definition

The data item records the version of the International Classification of diseases published by the World Health Organization (WHO).

Rationale

The development of the medical diagnoses over time requires regular adaptions of the International Classification of diseases. Switzerland used the ICD-8 for the coding of causes of death until 1994. Since 1995, the classification of causes of death in Switzerland is based on the World Health Organisation's (WHO) international statistical classification of diseases and related health problems, 10th revision (ICD-10).

Code	Label
8	ICD-8 Swiss version
10	ICD-10 WHO
11	ICD-11 WHO

National usage

The variable is to be submitted to the NACR.

References

>www.who.int/classifications/icd/en [last accessed: 27.12.2018].

>www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit/erhebungen/ecodhttps://www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit/nomenklaturen/medkk/instrumente-medizinische-kodierung.html
[last accessed: 29.12.2018].

Notes

>An adapted version of the ICD-8 WHO was used in Switzerland.

>Version ICD-9 was not used in Switzerland to code the cause of death.

>The date of death is the date of reference for the relevant ICD-version.

DIAGNOSIS

2.1   Date of informing the patient

Variable number: **2.1**

       Item length: 10

       Item format: Date (dd.mm.yyyy)

Definition

The data item records the date when the patient was informed according to KRG Art. 5 and KRV Art. 13. This date is a mandatory part of the patient's medical records. The physician responsible to inform the patient about the diagnosis is also responsible to inform about patient-relevant aspects of the cancer registration law, and to ensure documentation of the date.

Rationale

This date marks the information of the patient, or the person authorized to represent the patient, about the cancer registration.

Code examples[#]	Description
01.01.2005	Note: for single digit day or month, record with a leading zero.
…	

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR in truncated form; in all cases with day "not known" (i.e., 15th).

References

-

Notes

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2.2   Date of notification

Variable number: **2.2**

       Item length: 10

       Item format: Date (dd.mm.yyyy)

Definition

The data item records the date when the case was first notified to the registry.

Rationale

The time between incidence and registry notification is an important indicator for the timeliness of the registration process. It is also required for assessment of completeness of case ascertainment.

Code examples[#]	Description
01.01.2005	Note: for single digit day or month, record with a leading zero.
…	

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR in truncated form, with day set to unknown (i.e. 15) for all cases. In addition, the accompanying age in days will be submitted to the NACR.

References

-

Notes

>The date of notification may be before the date when the waiting period for potential patient veto to registration ends.

>Partially known dates are not accepted. Day, month and year must be provided.

>Based on practical considerations, the date of case creation in the registration software may be used.

2.3.1   Date of incidence

Variable number: **2.3.1**

    Item length: 10

    Item format: Date (dd.mm.yyyy)

Definition

The data item records the definite date of diagnosis.

The date of the first event (of the 7 listed below) to occur chronologically should be chosen as incidence date. If an event of higher priority occurs within three months of the date initially chosen, the date of the higher priority event should take precedence.

Order of declining priority:

1. Date of first histological or cytological (including flow cytometry, liquid biopsy) confirmation of this malignancy (with the exception of histology or cytology at autopsy).
This date should be, in the following order:

    a) date when the specimen was taken

    b) date specimen received by pathologist

    c) date of the pathology report.

2. Date of first positive genomic/molecular test diagnostic of this malignancy (see examples 1)

3. Date of admission to the hospital because of this malignancy.

4. When evaluated at an outpatient clinic only: date of first consultation at the outpatient clinic because of this malignancy.

5. Date of diagnosis, other than 1, 2, 3 or 4, for example:

    a) date of first positive tumour marker test diagnostic for this malignancy (see examples 2)

    b) date of first imaging (includes PET, CT or MRI) diagnostic for this malignancy

    c) date of multidisciplinary team meeting (MDT) for this malignancy.

6. Date of death, if no other information is available other than the fact that the patient has died because of a malignancy.

7. Date of death, if the malignancy is discovered at autopsy.

Whichever date is selected, the date of incidence should not be later than the date of the start of the treatment, or the decision not to treat, or the date of death. The choice of the date of incidence does not determine the coding of the item "basis of diagnosis".

Examples 1:

Examples of molecular tests that could be used to define incidence date

- T-cell receptor rearrangement – T-cell lymphoma

- BCR-ABL fusion gene (Philadelphia chromosome) – Chronic myeloid leukemia, acute lymphoblastic leukemia, and acute myelogenous leukemia
- JAK2 gene mutation – myeloproliferative neoplasms
- PML/RARα fusion gene – Acute promyelocytic leukaemia
- Circulating tumour DNA (ctDNA) – as part of diagnosis and cancer screening in future

Examples 2:
Examples of date of first positive tumour marker test diagnostic for this malignancy
- AFP in liver cancer
- Calcitonin in medullary thyroid carcinoma
- Chromogranin A in neuroendocrine tumours
- …

Rationale

The timing for staging and treatment begins with the date of incidence. Date of incidence is the starting point to calculate survival time.

Code examples[#]	Description
01.01.2005	Note: for single digit day or month, record with a leading 0.
15.01.2005	Note: if exact day unknown, set day as 15th of the respective month.
30.06.2005	Note: if exact day and month unknown, set date as 30th of June of the respective year.
…	

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR in truncated form, with day set to unknown (i.e. 15) for all cases.

References
>Recommendation issued by ENCR.
https://encr.eu/sites/default/files/Recommendations/ENCR%20Recommendation%20DOI_Mar2022_0.pdf
[last access: 18.09.2023]

Notes
-

2.3.2   Accuracy for date of incidence

Variable number: **2.3.2**

     Item length: 1

     Item format: Number

Definition

The data item indicates the accuracy of the date of incidence.

Rationale

The information is used to identify case groups where ages or time periods are not known with certainty (e.g. for sensitivity analyses).

Code	Label	Description
0	Exact date	All date components are known.
1	Day uncertain	The day in date is imputed.
2	Day/Month uncertain	The day and month in date are imputed.
3	Estimated date	All date components are imputed.

National usage

The variable is to be submitted to the NACR.

References

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Notes

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2.4   Age at incidence

Variable number: **2.4**

        Item length: 5

        Item format: Number

Definition

The data item indicates the age at the date of incidence, exact to the number of days.

Rationale

The information is used to compare cancer rates and outcomes by age.

Code examples[#]	Description
0	Diagnosed *in utero* or at day of birth
…	
99999	Unknown (Not stated / Not assessed).

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

-

Notes

>If more than a single diagnosis is registered per person, then the age at incidence may be different in each case.

2.5   DCN flag

Variable number: **2.5**

       Item length: 1

       Item format: Number

Definition

The data item identifies cases that first come to attention of the registries from death certificates (Death Certificate Notification).

Rationale

Unexpected high proportions of cases that first come to attention of the registries from death certificates are a potential problem for completeness of case ascertainment. DCN cases have to be traced back in order to find better information on this diagnosis (e.g. the incidence date). Cases with unsuccessful trace back are defined as DCO (Death Certificate Only), which serve as a quality measure for cancer registration.

Code	Label	Description
0	No	Not a DCN case.
1	Yes	DCN case.

National usage

The variable is to be submitted to the NACR.

References

>Bray, F and Parkin, DM. Evaluation of data quality in the cancer registry: Principles and methods. Part I: Comparability, validity and timeliness. Eur J Cancer 2008; 45: 747-755.

>Parkin, DM and Bray, F. Evaluation of data quality in the cancer registry: Principles and methods. Part II: Completeness. Eur J Cancer 2008; 45: 756-764.

Notes

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2.6   Method of first detection

Variable number: **2.6**
      Item length: 1
      Item format: Number

Definition
The data item records the method or circumstance by which the case came to medical attention and the cancer was first diagnosed.

Rationale
The information facilitates the interpretation of cancer incidence trends and the evaluation and monitoring of organized cancer screening programmes.

Code	Label	Description
1	Clinical symptoms	Clinical symptoms related to the tumour.
2	Incidental discovery	Diagnosis on the occasion of surveillance/treatment for another disease, incl. tumour aftercare for a previous primary tumour, routine medical consultation/routine check-up, surgery.
3	Organised screening program	Screening programmes organized at national or regional level, with an explicit policy, that includes several essential elements from target population to treatment. Screening refers to a targeted examination/search for an asymptomatic tumour.
4	Opportunistic screening	Screening outside an organized or population-based screening programme, as a result of, for example, a recommendation made during a routine medical consultation/check-up for the woman, on the basis of a possibly increased risk for developing cervical cancer or by self-referral. Screening refers to a targeted examination/search for an asymptomatic tumour.
5	Self-examination	Use this code if it is known that the chain of events leading to a diagnosis of cancer was a self-exam by the patient (e.g. a lump in the breasts, or a skin lesion).
6	Death with autopsy	Cancer diagnosed after death.
7	Death without autopsy	Cancer diagnosed after death.
8	Other	
9	Unknown	Not stated / Not assessed.

National usage
The variable is to be submitted to the NACR.

References
>IARC Handbooks of Cancer Prevention, Vol 7, 10, 17 etc. Lyon, http://publications.iarc.fr/Book-And-Report-Series/Iarc-Handbooks-Of-Cancer-Prevention.
>Erläuterungen zur KRV (11.4.2018). EDI, BAG.

Notes
>Registration of specific screening methods (i.e. occult blood test, colonoscopy, mammography, PSA test, etc.) has been postponed to future revisions of the KRG/KRV.

2.7   Most valid basis of diagnosis

Variable number: **2.7**

      Item length: 2

      Item format: Number

Definition

The data item records the most valid diagnostic procedure by which the tumour was confirmed. Validity increases from codes 0 to 8 (see Notes).

Rationale

The information indicates the precision and reliability of the diagnosis.

Code	Label	Description
0	Death Certificate Only (DCO)	Information provided is from a medical cause of death certificate (Death Certificate Only, DCO).
1	Clinical	Diagnosis made before death, but without any of the following (codes 2-8).
2	Clinical investigation	All diagnostic techniques without tissue diagnosis, including endoscopy, exploratory surgery (such as laparotomy) and autopsy.
3	Imaging	Radiology and other diagnostic imaging techniques without microscopic confirmation (x-Ray, ultrasound, etc.). Code 3 is not part of the ENCR recommendation or ICD-O. The quality of diagnostic imaging in some cases makes detailed differential diagnosis possible with a clinical impact equal to that of microscopic examination.
4	Specific tumour markers	Including biochemical and/or immunologic markers that are specific for a tumour site.
5	Cytology	Examination of cells from a primary or secondary site, including fluids aspirated by endoscopy or needle; also includes the microscopic examination of peripheral blood and bone marrow aspirates, immunophenotyping by flow cytometry and a liquid biopsy# in the absence of pathology.
7	Histology	Histologic examination of tissue from the tumour (primary or metastatic), however obtained, including all cutting techniques and bone marrow biopsies; also includes the examination of samples of the primary tumor from an autopsy.

7.1	Histology of primary tumour	Histologic examination of tissue from the primary tumour, however obtained, including all cutting techniques and bone marrow biopsies.
7.2	Histology of metastasis	Histology of the metastasis with no histology of the primary tumour.
7.3	Histology at autopsy	Histology of autopsy with no histology before autopsy.
8	Cytogenetic and/or molecular testing	Detection of tumour-specific genetic abnormalities or genetic changes in the tumour, including techniques such as karyotyping, FISH (fluorescent in situ hybridization), PCR (polymerase chain reaction), DNA sequencing.
9	Unknown	Basis of diagnosis not stated.

a liquid biopsy is a sample of blood or another body fluid (liquor, etc.) for the detection of cancer cells or DNAfragments of these tumour cells

National usage

The variable is to be submitted to the NACR.

References

> Recommendation issued by ENCR (2022). https://encr.eu/sites/default/files/Recommendations/ENCR Recommendation BoD_Oct2022_EN_241022.pdf [last access: 18.09.2023]

Notes

>Code 3 for Imaging does not imply higher validity as compared with code 2 for Clinical Investigation. In reporting the most valid basis of diagnosis, code 3 cases might have to be combined with code 2 cases.

2.8   Diagnostic method(s) used

Variable number: **2.8**

Item length: 2

Item format: Number

Definition

The data item records diagnostic methods used with a positive outcome.

Rationale

The information is the basis for decision-making on the most valid diagnostic procedure.

Code	Label
0	Death certificate notification
1	Clinical examination undefined
2	Clinical examination defined
3	Tumour clinically palpable
4	Radiodiagnostic of tumour (Xray)
5	Echography of tumour (ultrasound, sonography)
6	Scintigraphy of tumour (e.g. MIBG)
7	CT scan of tumour
8	MRI scan of tumour
9	Specific imaging of tumour (e.g. PET/CT, SPECT, fluorescent optical imaging)
10	Imaging to determine spread of disease (metastases)
11	Procedures without tissue examination (e.g. endoscopy, exploratory laparoscopy, exploratory laparotomy, autopsy)
12	Imaging NOS
13	Specific markers (biochemical or immunological)
14	Cytogenetic analysis (karyotype)
15	Specific genetic abnormalities or alterations in the tumour (FISH, SNP, MLPA, PCR, DNA sequence etc.)
16	Cytology NOS / Blood smear / peripheral blood / Immunophenotyping by flow cytometry
17	Cytology of tumour (e.g. fine needle aspirate/ PAP)
18	Bone marrow aspirate
19	Bone marrow biopsy
20	Biopsy unspecified
21	Biopsy/resection locoregional, without histology of primary tumour
22	Biopsy/resection of the metastasis, without histology of the primary tumour

23	Biopsy/resection locoregional or of the metastasis, without histology of the primary tumour
24	Biopsy of primary tumour
25	Biopsy and resection (z.B. melanoma)
26	Resection of the primary tumour
27	Autopsy with histological confirmation, without histology before autopsy
28	Liquid Biopsy
99	Unknown

National usage

The variable is to be submitted to the NACR.

References

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Notes

>Data providers can either report diagnostic method(s) individually, or submit already existing reports, which contain such information. The reported information must include the method with the highest validity, according to the data providers' knowledge. Variable 2.7 (Most valid basis of diagnosis) informs about different levels of validity.

>For this data item, address of the reporting institution(s) as well as report availability and report date could be registered.

2.9   Diagnostic institution(s)*

Variable number: **2.9**

      Item length: 255

      Item format: Text

Definition

The data item records the name and address of the responsible person and institution and submitting diagnostic information to the cancer registry.

Rationale

This information allows providing data quality feedback to those institutions requesting it. It also allows regional and national statistical reports on the relative contribution of different types of institutions to diagnosing cancer.

National usage

(*****) The variable is not to be submitted to the NACR.

References

>Medical practices: GLN (Global Location Number) www.refdata.ch/de/weitere-leistungen/swiss-rx-login

>Hospitals: official hospital lists www.bag.admin.ch/bag/de/home/zahlen-und-statistiken/zahlen-fakten-zu-spitaelern/spital-suchen.

Notes

>Addresses will be taken from national uniform lists of health service providers.

>Metadata for the institution responsible for diagnostics can also be registered to facilitate the exchange of information.

>The cancer registries define, and update on a regular basis, the official address of all responsible hospital units submitting cancer information.

>Multiple persons or institutions may optionally be registered per diagnosis.

2.10   Rank of diagnosis

Variable number: **2.10**
      Item length: 2
      Item format: Number

Definition

The data item records whether the diagnosis is the 1st, 2nd, etc. reportable primary neoplasms in the patient's lifetime.

Rationale

The type and existence of previously diagnosed reportable primary neoplasms has etiologic significance.

Code examples[#]	Label	Description
1	1st	The 1st cancer diagnosis in the patient's lifetime.
2	2nd	The 2nd cancer diagnosis in the patient's lifetime.
...	...	
99	Unknown	Rank of diagnosis not known.

#: only examples are shown to reduce table size

National usage

The variable will be generated by the NACR and then reported back to the cancer registries.

References

>www.iacr.com.fr/images/doc/MPrules_july2004.pdf

Notes

>Only primary diagnoses will be counted chronologically. Primary diagnoses are defined according to the International Rules for Multiple Primary Cancers (as issued by IACR, IARC, and ENCR).
>If several primary diagnoses occur at the same time, the most malignant has the lowest rank.

2.11   Case number

Variable number: **2.11**

          Item length: 10

          Item format: Number

Definition

The data item allocates a unique case number to the diagnosis. The number also indicates the FSO canton number of the patient address at the time of diagnosis by using the first two digits (e.g. "1" for canton ZH, "26" for canton JU). The federal Swiss Childhood Cancer Registry assigns "99" as first two digits.

Rationale

The case number serves as nation-wide unique identifier of the diagnosis.

Code examples[#]	Description
0912345678	Hypothetical case number in the Cancer Registry responsible for patients diagnosed while living in the canton of ZG.
9912345678	Hypothetical case number in the Swiss Childhood Cancer Registry who is responsible for all diagnoses in Switzerland in patients below 20 years of age at diagnosis.
…	

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

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Notes

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CLASSIFICATIONS (ICD, ICD-O)

> It is not required to generate information solely for the purpose of cancer registration. Only if relevant data items have already been assessed as part of diagnosis or treatment, the findings have to be submitted to the responsible cancer registry.

3.1 ICD version

Variable number: **3.1**

Item length: 2

Item format: Number

Definition

This data item records the version of the International Classification of diseases published by the World Health Organization (WHO) used to code the diagnosis.

Rationale

The International Classification of diseases (ICD) is the most important classification of morbidities worldwide. It is uniaxial and forms the basis for most types of cancer reporting to inform cancer control, research activity, treatment planning and health economics. It is regularly updated to include the progress in medical knowledge.

Code	Label	Description
10	ICD-10 WHO	English WHO version; or the official (FSO) translation of the WHO version into German (ICD-10-GM), French and Italian.
11	ICD-11 WHO	

National usage

The variable is to be submitted to the NACR.

References

>www.who.int/classifications/icd/en [last accessed: 27.12.2018].

>www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit/nomenklaturen/medkk/instrumente-medizinische-kodierung [last accessed: 29.12.2018].

Notes

>The German modification of ICD-10 (ICD-10-GM) is used in Switzerland. ICD-10-GM is based on ICD-10 (WHO) and is issued by the "Deutsches Institut für Medizinische Dokumentation und Information" (DIMDI). DIMDI issues yearly updates, which are implemented in Switzerland every two years.

3.2   ICD-O version

Variable number: **3.2**

        Item length: 2

        Item format: Number

Definition

The data item records the version of the International Classification of Diseases for Oncology (ICD-O).

Rationale

The International Classification of Diseases for Oncology (ICD-O) is a multiaxial classification coding separately for the site (topography) and the histology (morphology) of neoplasms. The ICD-O is internationally recognized as the definitive classification of neoplasms and is used by cancer registries throughout the world. Regularly updates incorporate the progress in medical knowledge.

Code	Label	Description
10	Version 1	
20	Version 2	
30	Version 3.0	WHO 2000
31	Version 3.1	Update 2011
32	Version 3.2	Update 2019

National usage

The variable is to be submitted to the NACR.

References

>Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S, editors. International Classification of Diseases for Oncology, third edition. Geneva, World Health Organization, 2000.

>Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S, editors. International Classification of Diseases for Oncology, Third edition, first revision. Geneva, World Health Organization, 2011.

Notes

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3.3   ICD code

Variable number: 3.3

       Item length: 5

       Item format: Alphanumeric

Definition

Disease code of the International Classification of diseases published by the World Health Organization (WHO). The item is entered without decimal point.

Rationale

The purpose of the ICD is to allow the systematic recording, analysis, interpretation and comparison of mortality and morbidity data collected in different countries or areas and at different times.

Code examples[#]	Label
C000	Malignant neoplasm of lip, external upper lip
…	

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>https://icd.who.int/browse10/2016/en [last accessed: 27.12.2018].

>www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit/nomenklaturen/medkk/instrumente-medizinische-kodierung [last accessed: 29.12.2018].

Notes

>The German modification of ICD-10 (ICD-10-GM) is used in Switzerland. ICD-10-GM is based on ICD-10 (WHO) and is issued by the "Deutschen Institut für Medizinische Dokumentation und Information" (DIMDI). DIMDI issues yearly updates, which are implemented in Switzerland every two years.

3.4   ICD-O Topography

Variable number: **3.4**

      Item length: 255

      Item format: Text

Definition

Identifies the primary site, or topography, of the neoplasm according to ICD-O. It is based on the most valid source of information. The item is entered without decimal point.

Rationale

Primary site determines the staging and treatment options. It also affects the prognosis and course of the disease. The data item is used to compare cancer rates and outcomes by site.

Code examples[#]	Label
C000	External upper lip
C809	Unknown primary site
…	

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S , editors. International Classification of Diseases for Oncology, third edition. Geneva, World Health Organization, 2000.

>Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S, editors. International Classification of Diseases for Oncology, Third edition, first revision. Geneva, World Health Organization, 2011.

Notes

-

3.5   ICD-O Morphology

Variable number: **3.5**

   Item length: 255

   Item format: Text

Definition

This data item records the microscopic anatomy or morphology of cells at time of diagnosis according to ICD-O.

Rationale

Morphology determines the staging and treatment options. It also affects the prognosis and course of the disease. The data item is used to compare cancer rates and outcomes by morphology.

Code examples[#]	Label	Description
8000	Neoplasm	Unclassified tumour
9992	Refractory thrombocytopenia	
...		

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S , editors. International Classification of Diseases for Oncology, third edition. Geneva, World Health Organization, 2000.

>Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S, editors. International Classification of Diseases for Oncology, Third edition, first revision. Geneva, World Health Organization, 2011.

Notes

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3.6.1   ICD-O Behaviour

Variable number: **3.6.1**

Item length: 1

Item format: Number

Definition

This data item records the behaviour of the neoplasm at time of diagnosis according to ICD-O.

Rationale

Behaviour determines the treatment options. It also affects the prognosis and course of the disease. The data item is used to compare cancer rates and outcomes by behaviour.

Code	Label	Description
0	Benign	Benign tumours do not metastasize or locally invade tissues.
1	Borderline	Uncertain whether benign or malignant. Low, borderline, or uncertain malignant potential.
2	In situ	Carcinoma in situ; intraepithelial; non-infiltrating; non-invasive.
3	Malignant	Invasive behaviour.
9	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

>Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S, editors. International Classification of Diseases for Oncology, third edition. Geneva, World Health Organization, 2000.

>Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S, editors. International Classification of Diseases for Oncology, Third edition, first revision. Geneva, World Health Organization, 2011.

Notes

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3.6.2   Associated in situ tumour

Variable number: **3.6.2**

         Item length: 1

         Item format: Number

Definition

This data item records the simultaneous presence of in situ and invasive tumour components.

Rationale

This information serves as prognostic factor, especially for breast cancer.

Code	Label	Description
0	No	
1	Yes	
9	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

> Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF): S3-Leitlinie Früherkennung, Diagnose, Therapie und Nachsorge des Mammakarzinoms, Version 4.0, 2017 AWMF Registernummer: 032-045OL, www.leitlinienprogramm-onkologie.de/leitlinien/mammakarzinom (4.5.2.7).

Notes

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3.7   ICD-O Histological grade

Variable number: **3.7**

        Item length: 1

        Item format: Number

Definition

The data item describes the neoplasm's resemblance to normal (parent) tissue according to ICD-O. Well differentiated (grade 1) is the most like normal tissue, and undifferentiated (grade 4) is the least like normal tissue. Codes 5 to 8 define particular cell lines for lymphoma and leukaemia.

Rationale

The information is useful for prognosis.

Code	Label	Description
1	Grade I	Well differentiated; Differentiated, NOS; Low grade; Nucleoli that are inconspicuous and basophilic at ×400 magnification.
2	Grade II	Moderately (well) differentiated; Intermediate differentiation; Nucleoli that are clearly visible at ×400 magnification and eosinophilic.
3	Grade III	Poorly differentiated; Dedifferentiated; High grade; Clearly visible nucleoli at ×100 magnification.
4	Grade IV	Undifferentiated; Anaplastic; Nucleoli with extreme pleomorphism or rhabdoid and/or sarcomatoid morphology.
5	T-cell	T-cell; T-precursor.
6	B-cell	B-cell; Pre-B; B-precursor.
7	Null cell	Null cell; Non-T-non-B.
8	NK cell	NK cell; Natural killer cell.
9	Unknown	Grade or differentiation not determined, not stated, or not applicable. Unknown primary.

National usage

The variable is to be submitted to the NACR.

References

>Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S, editors. International Classification of Diseases for Oncology, third edition. Geneva, World Health Organization, 2000.

>Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, Whelan S, editors. International Classification of Diseases for Oncology, Third edition, first revision. Geneva, World Health Organization, 2011.

Notes

>The WHO/ISUP grading for clear cell renal cell carcinoma and papillary renal cell carcinoma is based on the evaluation of nucleoli. Grades one to four are to be used for cases with ICD-O C64, M8310/3, M8260/3.

3.8 Laterality

Variable number: **3.8**

Item length: 1

Item format: Number

Definition

Laterality describes the side of a paired organ or side of the body on which the reportable cancer originated. A paired organ is one in which there are two separate organs of the same kind, one on either side of the body (e.g. kidney, breast, ovary, testis and lung).

Laterality should be coded for those paired organs for which such information may be relevant for clinical or epidemiological reasons: ICD-O-3 C07 (parotid gland), C09 (tonsil), C30.0 (nasal cavity), C34 (bronchus and lung with the exception C34.2), C38.4 (pleura), C40.0-40.3 (long/short bones), C41.3 (rib, clavicle), C41.4 (pelvic bones), C44.1 (skin of eyelid), C44.2 (skin of external ear), C44.6 (skin of arm and shoulder), C44.7 (skin of leg and hip), C50 (breast), C56 (ovary), C57.0 (fallopian tube), C62 (testis), C63.0 (epididymis), C64 (kidney), C65 (renal pelvis), C66 (ureter), C69 (eye), C74 (adrenal gland).

Rationale

Laterality information is required to determine the number of primaries involved.

Code	Label	Description
0	Not applicable	Midline tumour; unpaired organ.
1	Right	
2	Left	
3	Unilateral, NOS	Unilateral, but unknown whether right or left.
4	Bilateral	Origin of primary tumour is on both sides of a paired organ (when tumours of the same morphology are diagnosed simultaneously in both sides of a paired organ). Bilateral cancers are very rare, e.g. bilateral retinoblastoma, bilateral Wilms tumour of the kidney, or both ovaries involved simultaneously.
9	Unknown	It is unknown whether, for a paired organ, the reportable cancer was unilateral or bilateral.

National usage

The variable is to be submitted to the NACR.

References

>JRC Technical Report (version 1.1), 2018. A proposal on cancer data quality checks: one common procedure for European cancer registries. https://ec.europa.eu/jrc/en/publication/proposal-cancer-data-quality-checks-one-common-procedure-european-cancer-registries-version-11 [last access: 4.2.19].

Notes

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3.9.1   ICCC-3 main group

Variable number: **3.9.1**

> Item length: 2

> Item format: Alphanumeric

Definition

This data item records the main diagnostic group according to the third revision (2005) of the 1996 International Classification of Childhood Cancer (ICCC-3).

Rationale

ICCC-3 classifies tumours coded according to ICD-O-3 into 12 main groups, which allow standardised comparisons of the broad categories of childhood neoplasms. ICCC-3 was designed for use in international, population-based, epidemiological studies and cancer registries. In paediatric oncology the low frequency of cases requires the use of an international classification system to ensure data comparability between countries.

Code examples[#]	Label	Description
I	Leukaemia, myeloproliferative diseases, and myelodysplastic diseases.	ICD-O-3 codes: 9800, 9801, 9805, 9820, 9823, 9826, 9827, 9831-9837, 9840, 9860, 9861, 9863, 9866, 9867, 9870-9876, 9891, 9895-9897, 9910, 9920, 9930, 9931, 9940, 9945, 9946, 9948, 9950, 9960-9964, 9975, 9980, 9982-9987, 9989.
…		

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Steliarova-Foucher E et al. 2005. International Classification of Childhood Cancer, Third Edition. *Cancer* 2005; **103**:1457–67.

Notes

>There has been no update in ICCC-3 since 2005. Cases coded according to ICD-O-3.1 are assigned to the appropriate ICCC-3 group.

>The ICCC-3 codes are based on the ICD-O-3, and updates in the latter necessitate updates in the former.

>Among benign and borderline tumours, only those of the CNS should be classified according to ICCC-3 (Main group III and subgroup Xa).

3.9.2   ICCC-3 code*

Variable number: **3.9.2**

        Item length: 4

        Item format: Alphanumeric

Definition

This data item records detailed division of the diagnostic group according to the third revision of the 1996 International Classification of Childhood Cancer (ICCC-3).

Rationale

ICCC-3 classifies tumours coded according to ICD-O-3 into 12 main groups, which are split further into 47 subgroups. These 2 levels of the ICCC-3 allow standardised comparisons of the broad categories of childhood neoplasms. ICCC-3 was designed for use in international, population-based, epidemiological studies and cancer registries. In paediatric oncology the low frequency of cases requires the use of an international classification system to ensure data comparability between countries.

Code examples[#]	Label	Description
Ia	Lymphoid leukaemias	ICD-O-3 codes: 9820, 9823, 9826, 9827, 9831–9837, 9940, 9948.
XIIb	Other unspecified malignant tumours	ICD-O-3 codes: 8000-8005
…		

#: only examples are shown to reduce table size

National usage

(*) The variable is not to be submitted to the NACR. The NACR uses ICD-O information in statistics for children and adolescents.

References

>Steliarova-Foucher E et al. 2005. International Classification of Childhood Cancer, Third Edition. Cancer 2005; 103:1457–67.

Notes

>There has been no update in ICCC-3 since 2005. Cases coded according to ICD-O-3.1 are assigned to the appropriate ICCC-3 group.

>The ICCC-3 codes are based on the ICD-O-3, and updates in the latter necessitate updates in the former.

>Among benign and borderline tumours, only those of the CNS should be classified according to ICCC-3 (Main group III and subgroup Xa).

3.9.3 ICCC-3 extended code*

Variable number: **3.9.3**

Item length: 7

Item format: Alphanumeric

Definition

This data item records detailed division of the diagnostic group according to the third revision of the 1996 International Classification of Childhood Cancer (ICCC-3).

Rationale

ICCC-3 classifies tumours coded according to ICD-O-3 into 12 main groups, which are split further into 47 subgroups. These 2 levels of the ICCC-3 allow standardised comparisons of the broad categories of childhood neoplasms. The 16 most heterogeneous subgroups are broken down further into 2–11 divisions to allow the study of important entities or homogeneous collections of tumours characterized at the cytogenetic or molecular level. ICCC-3 was designed for use in international, population-based, epidemiological studies and cancer registries. In paediatric oncology the low frequency of cases requires the use of an international classification system to ensure data comparability between countries.

Code examples#	Label	Description
Ia.1	Precursor cell leukaemias	ICD-O-3 codes: 9835-9837
Ia.2	Mature B-cell leukaemias	ICD-O-3 codes: 9823, 9826, 9832, 9833, 9940
…		

#: only examples are shown to reduce table size

National usage

(*) The variable is not to be submitted to the NACR. The NACR uses ICD-O information in statistics for children and adolescents.

References

>Steliarova-Foucher E et al. 2005. International Classification of Childhood Cancer, Third Edition. Cancer 2005; 103:1457–67.

Notes

>There has been no update in ICCC-3 since 2005. Cases coded according to ICD-O-3.1 are assigned to the appropriate ICCC-3 group.

>The ICCC-3 codes are based on the ICD-O-3, and updates in the latter necessitate updates in the former.

STAGE, GRADE

> It is not required to generate information solely for the purpose of cancer registration. Only if relevant data items have already been assessed as part of diagnosis or treatment, the findings have to be submitted to the responsible cancer registry.

4.1   UICC TNM version

Variable number: **4.1**

      Item length: 3

      Item format: Number

Definition

The data item records the edition of the UICC (International Union Against Cancer) TNM Classification of Malignant Tumours. The classification is updated at irregular intervals.

Rationale

The UICC TNM Classification describes the anatomical extent (termed 'stage') of the disease. It also takes a number of non-anatomical prognostic factors into account. The data item is used to compare cancer rates and outcomes by stage. Stage is also useful for the evaluation of screening programs, and other studies.

Code	Label
10	Edition 1 (1968)
20	Edition 2 (1974)
30	Edition 3 (1987)
31	Edition 3, enlarged and revised (1982)
40	Edition 4 (1987)
42	Edition 4, enlarged and revised (1992)
50	Edition 5 (1997)
60	Edition 6 (2002)
70	Edition 7 (2009/2010)
71	Edition 7, enlarged and revised (2011)
80	Edition 8 (2017)

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5th Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

4.2 y-Prefix of cTNM

Variable number: **4.2**

    Item length: 1

    Item format: Number

Definition

The data item records the time of TNM assignment relative to therapy.

Rationale

To identify cases where T, N, and M classifications have been assigned during or following initial treatment as part of the first treatment complex. They can deviate from T, N, and M classifications at the time of diagnosis.

Code	Label	Description
0	No	TNM assigned before any therapy.
1	Yes	TNM assigned during or after neoadjuvant therapy.
9	Unknown	It cannot be assessed whether TNM was assigned before, during or after therapy.

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5th Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

Notes

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4.3 cT

Variable number: **4.3**

Item length: 10

Item format: Alphanumeric

Definition

The data item records tumour size based on clinical investigation, imaging, endoscopy, biopsy or surgical exploration.

Rationale

Treatment decisions are based on pre-therapeutic clinical assessment of tumour size. Clinical categories replace pathological categories if pathological data is not available or validated following neoadjuvant therapy.

Code examples[#]	Label	Description
X	cTX	Primary tumour cannot be assessed.
0	cT0	No evidence of primary tumour.
Is	cTis	Carcinoma in situ.
1	cT1	Confined to organ or part of the organ, small size lesion.
…		
88	NA	Not applicable. TNM classification not defined for this type of cancer.
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5th Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

Notes

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4.4   cN

Variable number: **4.4**

       Item length: 10

       Item format: Alphanumeric

Definition

The data item records regional lymph nodes involvement based on clinical investigation, imaging, endoscopy, biopsy or surgical exploration. Metastasis in any lymph node other than regional is classified as a distant metastasis.

Rationale

Treatment decisions are based on pre-therapeutic clinical assessment of regional lymph nodes involvement. Clinical categories replace pathological categories if pathological data is not available or validated following neoadjuvant therapy.

Code examples#	Label	Description
X	cNX	Regional lymph nodes cannot be assessed
0	cN0	No regional lymph node metastasis
1	cN1	
...		
88	NA	Not applicable. TNM classification not defined for this type of cancer.
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5th Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

Notes

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4.5   cM

Variable number: **4.5**

      Item length: 10

      Item format: Alphanumeric

Definition

The data item records the absence or presence of distant metastases based on clinical investigation, imaging, endoscopy, surgical exploration without biopsy.

Rationale

Treatment decisions are based on pre-therapeutic clinical assessment of distant metastases.

Code examples[#]	Code	Description
0	cM0	No distant metastasis.
1	cM1	Distant metastasis.
88	NA	Not applicable. TNM classification not defined for this type of cancer.
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5th Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

Notes

>MX for distant metastases cannot be assessed: not allowed for TNM editions 7 or higher.

4.6 a-Prefix of pTNM

Variable number: 4.6

Item length: 1

Item format: Number

Definition

The prefix a indicates that classification is first determined at autopsy.

Rationale

The information is used to stage cases of cancer by post mortem examination, using pathologic information obtained at the time of death.

Code	Label	Description
0	No	pTNM classification is not determined at autopsy.
1	Yes	pTNM classification is first determined at autopsy.
9	Unknown	No information whether pTNM is determined at autopsy or not.

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5th Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

Notes

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4.7   y-Prefix of pTNM

Variable number: **4.7**

          Item length: 1

          Item format: Number

Definition

The data item indicates whether TNM classification is performed during or following multimodality therapy (neoadjuvant radio- and/or chemotherapy prior to surgery).

Rationale

To identify cases where T, N, and M classifications have been assigned during or following initial treatments as part of the first treatment complex. They can deviate from T, N, and M classifications at the time of diagnosis.

Code	Label	Description
0	No	TNM assigned before any therapy.
1	Yes	TNM assigned during or after neoadjuvant therapy.
9	Unknown	It cannot be assessed whether TNM was assigned before, during or after therapy.

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5th Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

Notes

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4.8 pT

Variable number: **4.8**

Item length: 10

Item format: Alphanumeric

Definition

This data item records the extent of the primary tumour based on pathological (histological) evidence after completion of surgical therapy.

Rationale

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples#	Label	Description
X	pTX	Primary tumour cannot be assessed histologically.
0	pT0	No histological evidence of primary tumour.
Is	pTis	Carcinoma in situ.
1	pT1	Confined to organ or part of the organ, small size lesion.
…		
88	NA	Not applicable. TNM classification not defined for this type of cancer.
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5th Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

Notes

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4.9   m-Suffix of pT

Variable number: **4.9**

        Item length: 3

        Item format: Alphanumeric

Definition

The suffix m, in parentheses, is used to indicate the presence of multiple primary tumours at a single site. In the case of multiple primary tumours in one organ, the tumour with the highest T category should be classified and the multiplicity or the number of tumours should be indicated in parenthesis, e.g., T2(m) or T2(5). In simultaneous bilateral primary cancers of paired organs, each tumour should be classified independently.

Rationale

In tumours of the liver, ovary and fallopian tube, multiplicity is a criterion of T classification, and in tumours of the lung multiplicity may be a criterion of the M classification.

Code examples[#]	Label	Description
m	(m)	Unspecified multiplicity.
2	(2)	Two primary tumours.
…	…	
99	(99)	99 or more primary tumours.
999	Missing	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5th Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

Notes

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4.10   pN

Variable number: **4.10**

    Item length: 10

    Item format: Alphanumeric

Definition

The data item records the absence or presence and extent of regional lymph node metastasis, based on pathological evidence after completion of surgical therapy.

Rationale

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples[#]	Label	Description
X	pNX	Regional lymph nodes cannot be assessed histologically.
0	pN0	No regional lymph node metastasis histologically.
1	pN1	
…		
88	NA	Not applicable. TNM classification not defined for this type of cancer.
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5th Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

Notes

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4.11   Number of involved regional lymph nodes

Variable number: **4.11**

    Item length: 3

    Item format: Number

Definition

The data item records the number of regional lymph nodes examined by the pathologist and found to contain metastases.

Rationale

This information serves as a quality measure for pathologic reports.

Code examples#	Label	Description
0	None	No regional lymph node invaded.
1	1 node	One regional lymph node invaded.
...	...	
998	Number not exactly known	Regional lymph nodes were invaded, but no information on the number.
999	Unknown	No information whether regional lymph nodes were invaded or not.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

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Notes

>Register the lower limit x if "x or more were invaded" is reported.

4.12   Number of examined regional lymph nodes

Variable number: **4.12**

      Item length: 3

      Item format: Number

Definition

The data item records the total number of regional lymph nodes that were excised and examined by the pathologist.

Rationale

This information serves as a quality measure of the pathologic and surgical evaluation and treatment of the patient.

Code examples#	Label	Description
0	None	No regional lymph node examined.
1	1 node	One regional lymph node examined.
...	...	
998	Number not exactly known	Regional lymph nodes were examined, but no information on the number.
999	Unknown	No information whether regional lymph nodes were examined or not.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

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Notes

>Register the lower limit x if "x or more were examined" is reported.

4.13 pM

Variable number: **4.13**

    Item length: 10

    Item format: Text

Definition

The data item records the absence or presence of distant metastasis, based on pathological evidence after completion of surgical therapy or microscopic examination of metastasis.

Rationale

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples#	Label	Description
0	pM0	Is only to be used after autopsies.
1	pM1	Distant metastasis microscopically confirmed.
88	NA	Not applicable. TNM classification not defined for this type of cancer.
…		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5th Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

Notes

>MX ("distant metastases cannot be assessed") is not allowed for TNM 7th Edition or higher.

4.14 Lymphatic invasion

Variable number: **4.14**

      Item length: 1

      Item format: Number

Definition

The data item indicates the presence or absence of tumour cells in lymphatic vessels within and at the margins of the primary tumour, as well as afferent and efferent lymphatics, as noted microscopically by the pathologist.

Rationale

This information is an indicator for prognosis. It is recommended as an essential tumour related prognostic factor in breast cancer by UICC TNM-8.

Code	Label	Description
0	L0	No lymphatic invasion.
1	L1	Lymphatic invasion.
8	LX	Lymphatic invasion cannot be assessed.
9	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5th Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

Notes

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4.15   Venous invasion

Variable number: **4.15**

         Item length: 1

         Item format: Number

Definition

The data item indicates the presence or absence of tumour cells in the walls of venous blood vessels, as noted microscopically by the pathologist. There is no classification for invasion of arteries.

Rationale

This information is an indicator for prognosis. It is recommended as an essential tumour related prognostic factor in breast cancer by UICC TNM-8.

Code	Label	Description
0	V0	No venous invasion.
1	V1	Microscopic venous invasion.
2	V2	Macroscopic venous invasion.
8	VX	Venous invasion cannot be assessed.
9	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5th Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

Notes

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4.16   Perineural invasion

Variable number: **4.16**

         Item length: 1

         Item format: Number

Definition

Perineural invasion is the process of neoplastic invasion of nerves.

Rationale

This information is an indicator for prognosis.

Code	Label	Description
0	Pn0	No perineural invasion.
1	Pn1	Perineural invasion.
8	PnX	Perineural invasion cannot be assessed.
9	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5th Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

Notes

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4.17 TNM stage group

Variable number: **4.17**

Item length: 10

Item format: Alphanumeric

Definition

The data item records the UICC TNM stage group.

Rationale

For purposes of tabulation and analysis, it is useful to condense the anatomical extent of disease categories T, N, and M into groups.

Code examples#	Label	Description
0	0	Carcinoma in Situ.
I	I	Tumour localized to the organ of origin.
IV	IV	Distant metastasis.
…		
88	NA	Not applicable. TNM classification not defined for this type of cancer.
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5th Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

Notes

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4.18　　　　　　　　　　　Ann Arbor staging

Variable number:　　**4.18**

Item length:　10

Item format:　Alphanumeric

Definition

This data item is a last modification of the Ann Arbor classification for lymphoma.

Rationale

This information is increasingly used for prognosis estimation, pretreatment risk stratification, and selection of therapy and for outcome analysis. Ann Arbor is also part of International Prognostic Index (IPI) and modifications (mIPI, FLIPI etc.) for NHL.

Code examples#	Label	Description
I	Stage I	Cancer is located in a single lymph node region or single organ.
I+A	Stage I+A	Stage I without general symptoms.
IE+B	Stage IE+B	Stage I extralymphatic with general symptoms like weight loss, fever, night sweats.
IIIS+A	Stage IIIS+A	Stage III + spleen involvement without general symptoms.
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Carbone PP, Kaplan HS, Musshoff K, Smithers DW, Tubiana M (November 1971). "Report of the Committee on Hodgkin's Disease Staging Classification". Cancer Res. 31 (11): 1860–1. PMID 5121694.

>O'Sullivan B (ed. In chief), Brierley JD, D'Cruz AK, Fey MF, Pollock R, Vermorken JB, Huang SH (2015). Manual of Clinical Oncology. Ninth Edition. UICC. Wiley Blackwell & Sons, Ltd.

>Bruce D. Cheson, Richard I. Fisher et al. Recommendations for Initial Evaluation, Staging, and Response Assessment of Hodgkin and Non-Hodgkin Lymphoma: The Lugano Classification. J Clin Oncol 32:3059-3067. © 2014

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

Notes

>A or B symptoms will be recorded for Hodgkin Lymphoma (HL) only.

4.19 COG staging

Variable number: **4.19**

Item length: 10

Item format: Alphanumeric

Definition

This data item records staging of Wilms' tumour for pediatric patients acc. to pre-chemotherapy staging system developed by the National Wilms' Tumor Study Group (NWTSG). Based exclusively on the anatomic extent of the tumour, without consideration of genetic, biologic, or molecular markers.

Rationale

This staging system has been proven valuable in predicting outcomes.

Code	Label	Description
I	Stage I	Limited to kidney, not ruptured, no residual tumor.
II	Stage II	Extends beyond the kidney but is completely excised.
III	Stage III	Residual tumor confined to the abdomen. Micro/macroscopic remains of a tumour.
IV	Stage IV	Hematogenous / distant lymph nodes metastases.
V	Stage V	Bilateral renal involvement at diagnosis.
99	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

>Metzger ML, Dome JS. Current therapy for Wilms' tumour. Oncologist 2005;10: 815-26.

>Orkin S, Fisher D, Look A, Lux S, Ginsberg D, Nathan D. Oncology of Infancy and Childhood. Philadelphia, PA: Saunders, 2009.

Notes

>Used after surgical resection only, prior to chemotherapy.

>For Toronto staging do not use Stage V for bilateral tumours, but stage the kidney with the more advanced disease.

4.20   COG ALL staging

Variable number: **4.20**

   Item length: 10

   Item format: Alphanumeric

Definition

COG ALL staging (for childhood B- precursor acute lymphoblastic leukemia, B-ALL) allows a uniform assessment of the extent of CNS involvement based on presence of blasts in the diagnostic cerebrospinal fluid (CSF).

Rationale

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples#	Label	Description
CNS1	CNS1	No blasts in the CSF, regardless of WBC and RBC.
CNS2a	CNS2a	<5 WBC/mL + blasts + < 10 RBC/mL.
CNS3c	CNS3c	Clinical signs of CNS leukemia.
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Schulz KR, Pullen DJ, Sather HN et al. 2007 Risk- and response-based classification of childhood B-precursor acute lymphoblastic leukemia: a combined analysis of prognostic markers from the Pediatric Oncology Group (POG) and Children's Cancer Group (CCG) Blood. 2007 Feb 1; 109(3): 926–935.

>Winick N, Devidas M, Chen S et al. 2017 Impact of Initial CSF Findings on Outcome Among Patients With National Cancer Institute Standard- and High-Risk B-Cell Acute Lymphoblastic Leukemia: A Report From the Children's Oncology Group 2017 J Clin Oncol 35:2527-2534.

Notes

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4.21 FIGO staging

Variable number: **4.21**

Item length: 10

Item format: Alphanumeric

Definition

FIGO Staging of gynecologic tumours is based on clinical staging, careful clinical examination before therapy, and surgical exploration.

Rationale

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples#	Label	Description
I	Stage I	Tumour limited to organ of origin.
II	Stage II	Extension beyond organ.
…		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5th Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

Notes

>Cervix carcinoma: FIGO is based on clinical staging.

>FIGO stage requires known UICC TNM version.

4.22 INRGSS staging

Variable number: **4.22**

    Item length: 10

    Item format: Alphanumeric

Definition

This data item records the paediatric stage classification of the International Neuroblastoma Risk Group Staging System (INRGSS).

Rationale

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes. INRGSS is recommended by UICC TNM-8.

Code	Label	Description
L1	Stage L1	Localized tumour not involving vital structures as defined by the list of image-defined risk factors and confined to one body compartment.
L2	Stage L2	Locoregional tumor with presence of one or more image-defined risk factors.
M	Stage M	Distant metastatic disease (except stage MS).
MS	Stage MS	Metastatic disease in children younger than 18 months with metastases confined to skin, liver, and/or bone marrow.
99	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

>Monclair T, Brodeur GM, Ambros PF, Brisse HJ, Cecchetto G, Holmes K, u. a. The International Neuroblastoma Risk Group (INRG) Staging System: An INRG Task Force Report. J Clin Oncol. 10. Januar 2009;27(2):298–303.

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

>Patients with multifocal primary tumors should be staged according to the greatest extent of disease as defined in the table.

4.23 IRSS staging

Variable number: **4.23**

    Item length: 10

    Item format: Alphanumeric

Definition

The paediatric International Retinoblastoma Staging System is based on extent of disease and the presence of overt extra-ocular extension after enucleation.

Rationale

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples[#]	Label	Description
0	Stage 0	Patients treated conservatively. The tumour is confined to the globe. Enucleation has not been performed.
0 (A)	Stage 0 Group A	Very low risk of losing the eye(s). Small tumours, 3 millimeters (mm) or smaller, only in the retina not near the foveola or the optic nerve. No tumours are floating in the eye, (vitreous seeding). No retinal detachment.
pI	pStage I	Eye enucleated, completely resected histologically.
cIVa.1	cStage IVa.1	Haematogenous metastasis (without CNS involvement): single lesion.
…		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Chantada G, Doz F, Antoneli CBG et al. A Proposal for an International Retinoblastoma Staging System Pediatr Blood Cancer 2006;47: 801–805.

>Chantada G, Sampor C, Bosaleh A et al. Comparison of Staging Systems for Extraocular Retinoblastoma JAMA Ophthalmol 2013: doi:10.1001/jamaophthalmol.2013.260.

>Fabian ID, Reddy A, and Sagoo MS. Classification and staging of retinoblastoma. Community Eye Health 2018 31: 11-13.

Notes

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4.24   Lugano staging

Variable number: **4.24**

    Item length: 10

    Item format: Alphanumeric

Definition

The data item is a modification of the Ann Arbor classification for lymphoma.

Rationale

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples#	Label	Description
I	Stage I	Cancer is located in a single lymph node region or single organ.
I+A	Stage I+A	Stage I without general symptoms
IE+B	Stage IE+B	Stage I extralymphatic with general symptoms like weight loss, fever, night sweats.
II bulky	Stage II bulky	Stage II + single nodal mass >10 cm in max dimension or > a third of the thoracic diameter as assessed on CT.
IIIS+A	Stage IIIS+A	Stage III + spleen involvement without general symptoms
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Cheson BD, Fisher RI, Barrington SF, et al. Recommendations for initial evaluation, staging, and response assessment of Hodgkin and non-Hodgkin lymphoma: the Lugano classification. J Clin Oncol 2014; 32: 3059–3068.

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

>A or B symptoms will be recorded for Hodgkin Lymphoma (HL) only.

4.25 PRETEXT staging

Variable number: **4.25**

Item length: 10

Item format: Alphanumeric

Definition

The PRETEXT (PRE-Treatment EXTent of tumor) staging system is used for malignant primary liver tumours of childhood before any therapy. The PRETEXT hepatoblastoma staging is based on Couinaud's system of segmentation of the liver.

Rationale

This staging system has very good prognostic value.

Code examples#	Label	Description
I	PRETEXT I	One section is involved and three adjoining sections are free.
II	PRETEXT II	One or two sections are involved, but two adjoining sections are free.
…		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Roebuck DJ, Aronson D, Clapuyt P, et al. 2005 PRETEXT: a revised staging system for primary malignant liver tumours of childhood developed by the SIOPEL group. Pediatric Radiol 2007; 37: 123–132.

>Towbin AJ, Meyers RL, Woodley H, et al. 2017 PRETEXT: radiologic staging system for primary hepatic malignancies of childhood revised for the Paediatric Hepatic International Tumour Trial (PHITT). Pediatric Radiology (2018) 48:536–554.

Notes

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4.26   Rai staging

Variable number: **4.26**

>   Item length: 10
>   Item format: Alphanumeric

Definition

This classification for Chronic Lymphocytic Leukaemia (CLL) includes 4 stages based on blood and bone marrow cell count (lymphocytes, platelets), haemoglobin/haematocrit, LN envolement, hepato- and/or splenomegaly. The staging allows classification of patients into three risk categories (low, intermediary, high risk with median survival >12y, >8y and >2y, respectively).

Rationale

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples#	Label	Description
0	Stage 0	Lymphocytosis, lymphocytes in the blood >15.000/µL and >40% lymphocytes in the bone marrow. Low risk.
I	Stage I	Stage 0 with enlarged LN. Intermediary risk.
III	Stage III	Stage 0-II with Hb <11.0 g/dl or 92aematocrit <33%. High risk.
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Rai KR. A critical analysis of staging in CLL. In: Gale RP, Rai KR, eds. Chronic Lymphocytic Leukemia: Recent Progress and Future Directions. New York, NY: Liss; 1987:253-264.

>Rai KR, Sawitsky A, Cronkite EP, Chanana AD, Levy RN and Pasternack BS. Clinical staging of chronic lymphocytic leukemia. Blood 1975; 46: 219-234.

Notes

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4.27 Binet staging

Variable number: **4.27**

    Item length: 2

    Item format: Alphanumeric

Definition

This data item records the stage of Chronic Lymphocytic Leukaemia (CLL) based on the cell count in the blood and bone marrow (lymphocytes, platelets), haemoglobin/ haematocrit, lymph nodes involvement, hepato- and/or splenomegaly.

Rationale

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code	Label	Description
A	Stage A	Hb ≥ 10.0 g/dl, thrombocytes ≥100 × 109/l, <3 lymph node regions.
B	Stage B	Hb ≥ 10.0 g/dl, thrombocytes ≥100 × 109/l, ≥3 lymph node regions.
C	Stage C	Hb < 10.0 g/dl, thrombocytes <100 × 109/l, any number of lymph node regions.
99	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

>Binet JL, Auquier A, Dighiero G, Chastang C, Piguet H, Goasguen J et al. A new prognostic classification of chronic lymphocytic leukemia derived from a multivariate survival analysis. Cancer 1981; 48: 198-206.

Notes

>Binet's lymphoid areas consist in: lymphadenopathy either uni- or bilateral in (1) cervical, (2) axillary, (3) inguinal areas, (4) spleen, (5) liver.

4.28　　　　　　　　　Rhabdomyosarcoma site staging

Variable number:　**4.28**

　　　Item length:　3

　　　Item format:　Alphanumeric

Definition

Rhabdomyosarcoma staging is based on the classic TNM staging taking into account favourable/non-favourable tumour sites. It is used in paediatric oncology.

Rationale

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples#	Label	Description
I	Stage I	Any T, Any N, M0, Favourable Site.
IV	Stage IV	Any T, Any N, M1, Any Grade.
…		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

>The prognostic grouping for rhabdomyosarcoma includes favourable anatomic sites and unfavourable anatomic sites.

>Favourable anatomic sites: orbit, head and neck (excluding parameningeal tumours) and genitourinary sites (excluding bladder and prostate tumours).

>Non-favourable sites: bladder, prostate, extremity, cranial, parameningeal, trunk, retroperitoneum and all other sites not noted as favourable

4.29   ISS staging

Variable number: **4.29**
       Item length: 3
       Item format: Alphanumeric

Definition

The data item records the International Staging System (ISS) for multiple myeloma.

Rationale

This information isused to estimate prognosis, evaluate new types of therapy, and analyse outcomes. Simple and powerful prognostic staging system.

Code	Label	Description
I	Stage I	Serum β2-microglobulin level < 3.5 mg/L and serum albumin level > 3.5 g/dL.
II	Stage II	(Not ISS stage I or III).
III	Stage III	Serum β2-microglobulin level ≥ 5.5 mg/L.
99	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

>Greipp PR, Miguel JS, Durie BGM, Crowley JJ, Barlogie B, Bladé J, u. a. International Staging System for Multiple Myeloma. *J Clin Oncol* 2005; **23**(15):3412–20.

Notes

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4.30   DSSplus

Variable number: **4.30**

 Item length: 5

 Item format: Alphanumeric

Definition

The DSSplus (Durie-Salmon Plus staging system) is the revised Durie-Salmon staging system for multiple myeloma classification, based on MRI findings, FDG PET/CT findings, or both.

Rationale

This information is used to estimate prognosis, evaluate optimal therapy, and analyse outcomes.

Code	Label	Description
IA	Stage IA	Smoldering or indolent. Can have single plasmocytoma or limited disease at imaging; Normal renal function (serum creatinine level < 2.0 mg/dL).
IB	Stage IB	< 5 focal lesions, mild diffuse disease; Abnormal renal function (serum creatinine level ≥ 2.0 mg/dL).
IIA	Stage IIA	5–20 focal lesions; moderate diffuse disease; Normal renal function (serum creatinine level < 2.0 mg/dL).
IIB	Stage IIB	5–20 focal lesions; moderate diffuse disease; Abnormal renal function (serum creatinine level ≥ 2.0 mg/dL).
IIIA	Stage IIIA	> 20 focal lesions; moderate diffuse disease; normal renal function (serum creatinine level < 2.0 mg/dL).
IIIB	Stage IIIB	> 20 focal lesions; moderate diffuse disease; Abnormal renal function (serum creatinine level ≥ 2.0 mg/dL).
99	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

>Durie BG, Kyle RA, Belch A, et al. Myeloma management guidelines: a consensus report from the scientific advisors of the International Myeloma Foundation. *Hematol J* 2003; **4** (6): 379 – 398.

Notes

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4.31 SIOP staging

Variable number: **4.31**

    Item length: 10

    Item format: Alphanumeric

Definition

This data item records staging of Wilms' tumor for pediatric patients acc. to post-chemotherapy staging system developed by the International Society of Pediatric Oncology (SIOP). Based exclusively on the anatomic extent of the tumor, without consideration of genetic, biologic, or molecular markers.

Rationale

This staging system has been proven valuable in predicting outcomes.

Code examples#	Label	Description
yI	Stage y-I	Confined to kidney, capsule not exceeded, tumour can be completely removed.
yII	Stage y-II	Tumour infiltrates adjacent organs but is completely resected.
yIII	Stage y-III	Incomplete removal, no hematogenous metastases. Regional lymph nodes involved.
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Metzger ML, Dome JS. Current therapy for Wilms' tumor. Oncologist 2005;10: 815-26.

>Orkin S, Fisher D, Look A, Lux S, Ginsberg D, Nathan D. Oncology of Infancy and Childhood. Philadelphia, PA: Saunders, 2009.

Notes

>Used after chemotherapy only, prior to chemotherapy use Children's Oncology Group (COG) /National Wilms Tumour Study Group (NWTSG) staging (Variable 4.19).

>For Toronto staging do not use Stage V for bilateral tumours but stage the kidney with the more advanced disease.

4.32 St. Jude / Murphy staging

Variable number: **4.32**

Item length: 5

Item format: Alphanumeric

Definition

The St Jude/Murphy staging system for childhood NHL is based on clinical-pathological features like physical examination, CBC, imaging, bone marrow, CSF examinations etc.

Rationale

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes.

Code examples[#]	Label	Description
I	Stage I	Involvement of a single tumour mass or nodal area, excluding the mediastinum and abdomen.
IV	Stage IV	Involvement of bone marrow and/or central nervous system.
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Murphy S. Classificaton, staging and end results of treatment in childhood non-Hodgkin's lymphoma: dissimilarities from lymphomas in adults. *Semin Oncol.* (1980); **7**:332–9.

Notes

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4.33.1   Toronto Tier II staging

Variable number: **4.33.1**

       Item length: 255

       Item format: Text

Definition

The Toronto Paediatric Cancer Stage Guidelines recommend the malignancy-specific staging system most suitable for use by population registries for 16 of the most common childhood malignancies. The Guidelines include a two-tiered approach that provides less detailed criteria for registries with limited resources and/or limited data access (Tier 1) based on collapsing of the more detailed criteria (Tier 2).

Rationale

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes. The appropriate staging system will be used to generate Toronto Tier II staging, e.g. Ann Arbor for Hodgkin's lymphomas, St. Jude-Murphy for non-Hodgkin lymphoma, TNM for rhabdomyosarcoma, etc.

Disease	Staging system	Code examples#
Acute lymphoblastic leukaemia	COG ALL	CNS1
Acute myeloid leukaemia	Toronto	CNS positive
Hodgkin lymphoma	Ann-Arbor	stage IA/B
Non-Hodgkin lymphoma	St. Jude/Murphy	stage I
Neuroblastoma	INRGSS	L1
Wilms tumour	COG	Stage I
Wilms tumour	SIOP	Stage y-I
Rhabdomyosarcoma, non-rhabdomatous soft tissue sarcoma	TNM	TNM stage I
Retinoblastoma	IRSS	Stage 0
Hepatoblastoma	PRETEXT	I
Testicular cancer	TNM	TNM stage I
Ovarian cancer	FIGO	FIGO stage I
All diseases	Not stated / Not assessed.	99

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Gupta S, Aitken JF, Bartels U, Brierley J, Dolendo M, Friedrich P, et al. Paediatric cancer stage in population-based cancer registries: the Toronto consensus principles and guidelines. The Lancet Oncology. 2016;17(4):e163-72.

Notes

>Toronto Tier I will be generated from Toronto Tier II.
>See the individual staging systems for further details.

4.33.2   Toronto Tier II (manual) staging

Variable number: **4.33.2**

    Item length: 10

    Item format: Text

Definition

The Toronto Paediatric Cancer Stage Guidelines recommend the malignancy-specific staging system most suitable for use by population registries for 16 of the most common childhood malignancies. The Guidelines include a two-tiered approach that provides less detailed criteria for registries with limited resources and/or limited data access (Tier 1) based on collapsing of the more detailed criteria (Tier 2).

Rationale

This information is used to estimate prognosis, evaluate new types of therapy, and analyse outcomes. This variable will be used where no other standard staging system is available, e.g. for ependymomas, medulloblastomas and other CNS embryonal tumours as well as Ewings's sarcoma and osteosarcoma.

Code examples[#]	Label	Description
M3	M3	Visible metastasis in spine or visible metastasis in cervicomedullary (junction).
Metastatic	Metastatic	Used for Ewing's sarcoma or osteosarcoma with distant metastases present at diagnosis. Although more detailed staging systems exist their clinical and prognostic value is limited, multi-tiered staging systems were not deemed appropriate.
...		
99	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>Gupta S, Aitken JF, Bartels U, Brierley J, Dolendo M, Friedrich P, et al. Paediatric cancer stage in population-based cancer registries: the Toronto consensus principles and guidelines. The Lancet Oncology. 2016;17(4):e163-72.

Notes

>Toronto Tier I will be generated from Toronto Tier II.

4.34   Creasman grading system

Variable number: **4.34**

        Item length: 1

        Item format: Number

Definition

This data item records histopathological grade for uterine or endometrial cancer.

Rationale

Creasman grading is recommended as an essential tumour related prognostic factor by UICC TNM-8.

Code	Label	Description
1	G1	≤5% of a nonsquamous or nonmorular solid growth pattern
2	G2	6–50% of a nonsquamous or nonmorular solid growth pattern
3	G3	>50% of a nonsquamous or nonmorular solid growth pattern
9	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

>Creasman WT, Odicino F, Maisonneuve P, Quinn MA, Beller U, Benedet JL, Heintz APM, Ngan HYS, Pecorelli S. FIGO Annual Report on the results of treatment in gynaecological cancer. Vol. 26. Carcinoma of the corpus uteri. Int J Gynecol Obstet 2006; 95 (Suppl. 1): 105–143.

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

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4.35   Elston/Ellis grading system

Variable number: **4.35**

       Item length: 1

       Item format: Number

Definition

This data item records the histopathological grade for breast cancer. It is also called the Nottingham Histological Score. The grade for an individual tumour is derived from an assessment of three morphological features (Tubule formation, Nuclear pleomorphism, Mitotic count), each of which is scored 1-3.

Rationale

The information is recommended as an essential tumour related prognostic factor by UICC TNM-8.

Code	Label	Description
1	grade I	well-differentiated
2	grade II	moderately differentiated
3	grade III	poorly differentiated
9	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

>Elston CW, Ellis IO. Pathological prognostic factors in breast cancer. I. The value of histological grade in breast cancer: experience from a large study with long term follow up. Histopathology 1991; 19: 403–410.

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

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4.36   SalzerKuntschik grading system

Variable number: **4.36**

     Item length: 1

     Item format: Number

Definition

This data item records the grade of morphological regression for malignant bone tumour in children after chemotherapy.

Rationale

This information is an important prognostic factor, as well as for planning surgical treatment.

Code	Label	Description
1	I	No vital tumour cells.
2	II	Single vital tumour cells or vital cell clusters <0.5 cm.
3	III	<10% vital tumour in the total tumor mass.
4	IV	10-50% vital tumour in the total tumor mass.
5	V	>50% vital tumour cells in the total tumor mass.
6	VI	No tumour response.
9	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

>Salzer-Kuntschik M et al. Morphological grades of regression in osteosarcoma after polychemotherapy - study COSS 80. J Cancer Res Clin Oncol 1983;106 Suppl:21-4.

Notes

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4.37 Shimada grading system

Variable number: **4.37**

Item length: 1

Item format: Number

Definition

This data item records the grade for neuroblastoma, a frequent childhood cancer. Based on a grade of neuroblastic differentiation and mitosis-karyorrhexis index [MKI]) along with patient age at the time of diagnosis.

Rationale

Imortant prognostic factor for neuroblastoma.

Code	Label	Description
1	Favourable Histology	Age <1.5 yrs: Poorly differentiated or differentiating and low or intermediate MKI tumor. Age 1.5–5.0 yrs: Differentiating and low MKI tumor.
2	Unfavourable Histology	Age < 1.5 yrs 1) Undifferentiated tumor; 2) high MKI (mitosis-karyorrhexis index) tumor. Age 1.5–5.0 yrs 1) Undifferentiated and/or high MKI tumour 2) poorly differentiated and/or intermediate MKI tumour. Age > 5.0 yrs: All tumors.
9	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

>Shimada H, Ambros IM, Dehner LP et al. The International Neuroblastoma Pathology Classification (the Shimada System) Cancer 1999; 86:364–72.

>Shimada H, Chatten J, Newton WA, et al. Histopathologic prognostic factors in neuroblastic tumours: definition of subtypes of ganglioneuroblastoma and an age-linked classification of neuroblastomas. J Natl Cancer Inst 1984; 73:405–16.

>Shimada H, Umehara S, Monobe Y et al. International neuroblastoma pathology classification for prognostic evaluation of patients with peripheral neuroblastic tumours: a report from the Children's Cancer Group Cancer 2001; 92:2451-61.

Notes

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4.38   WHO(CNS) grading system

Variable number: **4.38**

   Item length: 1

   Item format: Number

Definition

Primary brain tumours are grouped according to the WHO classification based on the cell of origin, and the histological aggressiveness.

Rationale

The grade is widely used to evaluate prognosis, as well as to plan treatment.

Code	Label	Description
1	Grade I	Tumours with low proliferative potential and possibility of cure after resection.
2	Grade II	Tumours are infiltrative in nature and often recur despite low level of proliferation, or progress to higher grades.
3	Grade III	Clear evidence of malignancy, incl. nuclear atypia and brisk mitotic activity.
4	Grade IV	Cytologically malignant, mitotic active, necrosis-prone lesions with widespread infiltration of surrounding tissue and a propensity of craniospinal dissemination.
9	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

>WHO Classification of Tumours of the Central Nervous System, Revised Fourth Edition. Louis, D.N., Ohgaki, H., Wiestler, O.D., Cavenee, W.K. IARC Lyon 2016.

Notes

>WHO grading system for CNS is a malignancy scale, rather than a strict histological grading system, and therefore does not parallel the ICD-O-3 grade code.

4.39 Clinical tumour size

Variable number: **4.39**

Item length: 3

Item format: Number

Definition

The data item records the largest preoperative dimension or diameter of the tumour, in mm.

Rationale

This numeric information serves to cross-check the categorical information submitted as cT. It also serves to code the size of tumours where cT does not apply (e.g. brain cancer).

Code examples[#]	Label	Description
1		Size is 1 mm.
2		Size is 2 mm.
...		
998		Size is 998 mm or more.
999	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

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Notes

>Use code "1" if tumour diameter or the largest extension is provided with precision of one decimal place, and if diameter ≥0.1 and ≤0.9 mm. Round to the nearest integer if diameter >1.0.
>0 mm is not a valid code (e.g. in the case of CUP). The variable is left empty.

4.40   Pathological tumour size

Variable number: **4.40**

         Item length: 3

         Item format: Number

Definition

The data item records the largest postoperative dimension or diameter of the tumour, in mm.

Rationale

This numeric information serves to cross-check the categorical information submitted as pT. It also serves to code the size of tumours where pT does not apply (e.g. brain cancer).

Code examples[#]	Label	Description
1		Size is 1 mm.
2		Size is 2 mm.
…		
998		Size is 998 mm or more.
999	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR

References

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Notes

>Use code "1" if tumour diameter or the largest extension is provided with precision of one decimal place, and if diameter ≥0.1 and ≤0.9 mm. Round to the nearest integer if diameter >1.0.

>0 mm is not a valid code (e.g. after neoadjuvant therapy). The variable is left empty.

4.41   Metastases at diagnosis indicator

Variable number: **4.41**

       Item length: 1

       Item format: Number

Definition

The data item identifies the presence of metastases at time of diagnosis.

Rationale

This variable serves also to register metastases for sites such as CNS tumours, where TNM is not applicable.

Code	Label	Description
0	No	
1	Yes	
9	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.

> Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

> Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

Notes

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4.42 Topography of metastases at diagnosis

Variable number: **4.42**

Item length: 2

Item format: Number

Definition

The data item identifies the distant site(s) of metastatic involvement at time of diagnosis.

Rationale

The topography of metastases at diagnosis is an independent prognostic indicator. This variable serves also to record metastases for leukaemias or CNS tumours where TNM is not applicable.

Code	Label	Description
1	PUL	Pulmonary (C34).
2	OSS	Osseous (C40, 41).
3	HEP	Hepatic (C22).
4	BRA	Brain (C71).
5	LYM	Lymph nodes (C77).
6	MAR	Bone marrow (C42.1).
7	PLE	Pleura (C38.4).
8	PER	Peritoneum (C48.1, 2).
9	ADR	Adrenals (C74).
10	SKI	Skin (C44).
11	OTH	Others.
99	UNK	No information on the topography of metastases available, e.g. poly-metastatic disease.

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

Notes

>If the patient has multiple metastases, more than one topography is registered for the primary tumour.

BREAST CANCER:
tumour related
prognostic factors

> It is not required to generate information solely for the purpose of cancer registration. Only if relevant data items have already been assessed as part of diagnosis or treatment, the findings have to be submitted to the responsible cancer registry.

5.1.1   Oestrogen receptor status

Variable number: **5.1.1**

       Item length: 3

       Item format: Number

Definition

The data item records the oestrogen receptor expression status of the tumour.

Rationale

The information is listed as an essential prognostic factor in TNM-8 for breast cancer. The oestrogen receptor (ER) is a cell protein that stimulates the cell proliferation under the influence of oestrogen. The ER status predicts whether breast cancer will response to hormonal therapy (or the removal of the ovaries) suppressing the oestrogen receptors and thus inhibiting tumour growth.

Code examples[#]	Label	Description
>0	Percentage value (%)	Use if quantitative information is provided.
...		
100	Percentage value (%)	Use if quantitative information is provided.
222	Receptor status negative	Use if qualitative information is provided. Use if 0% value is provided.
333	Receptor status positive	Use if qualitative information is provided.
888	Receptor status not performed	
999	Receptor status unknown	No information available.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>O'Sullivan B (ed. In chief), Brierley JD, D'Cruz AK, Fey MF, Pollock R, Vermorken JB, Huang SH (2015). Manual of Clinical Oncology. Ninth Edition. UICC. Wiley Blackwell & Sons, Ltd.

>Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF): S3-Leitlinie Früherkennung, Diagnose, Therapie und Nachsorge des Mammakarzinoms, Version 4.0, 2017 AWMF Registernummer: 032-045OL, www.leitlinienprogramm-onkologie.de/leitlinien/mammakarzinom (4.5.2.7).

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

>If both, quantitative and qualitative information is known, the quantitative is to be reported.

5.1.2 Progesterone receptor status

Variable number: **5.1.2**

    Item length: 3

    Item format: Number

Definition

The data item records the progesterone receptor expression status of the tumour.

Rationale

The information is listed as an additional prognostic factor in TNM-8 for breast cancer. The Progesterone receptor (PR) status is used to predict whether or not a patient will benefit from endocrine therapy suppressing progesterone receptors and inhibiting the tumour growth.

Code examples[#]	Label	Description
>0	Percentage value (%)	Use if quantitative information is provided.
...		
100	Percentage value (%)	Use if quantitative information is provided.
222	Receptor status negative	Use if qualitative information is provided. Use if 0% value is provided.
333	Receptor status positive	Use if qualitative information is provided.
888	Receptor status not performed	
999	Receptor status unknown	No information available.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>O'Sullivan B (ed. In chief), Brierley JD, D'Cruz AK, Fey MF, Pollock R, Vermorken JB, Huang SH (2015). Manual of Clinical Oncology. Ninth Edition. UICC. Wiley Blackwell & Sons, Ltd.

>Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF): S3-Leitlinie Früherkennung, Diagnose, Therapie und Nachsorge des Mammakarzinoms, Version 4.0, 2017 AWMF Registernummer: 032-045OL, www.leitlinienprogramm-onkologie.de/leitlinien/mammakarzinom (4.5.2.7).

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

>If both, quantitative and qualitative information is known, the quantitative is to be reported.

5.1.3   Her2 receptor status

Variable number: **5.1.3**

      Item length: 1

      Item format: Number

Definition

The data item records the Her2 (human epidermal growth factor receptor 2) expression status of the tumour.

Rationale

The information is listed as an essential prognostic factor in TNM-8 for breast cancer. The Her2 receptor is an oncogene that can influence cell proliferation and tumour genesis. Its overexpression is associated with aggressive histological features of the tumour and poor prognosis and allows effective cancer management by Her2-targeting therapy.

Code	Label
1	Her2 overexpressed or gene amplified
2	Her2 not overexpressed or gene not amplified
3	Not performed
9	Unknown whether performed or not

National usage

The variable is to be submitted to the NACR.

References

>O'Sullivan B (ed. In chief), Brierley JD, D'Cruz AK, Fey MF, Pollock R, Vermorken JB, Huang SH (2015). Manual of Clinical Oncology. Ninth Edition. UICC. Wiley Blackwell & Sons, Ltd.

>Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF): S3-Leitlinie Früherkennung, Diagnose, Therapie und Nachsorge des Mammakarzinoms, Version 4.0, 2017 AWMF Registernummer: 032-045OL, www.leitlinienprogramm-onkologie.de/leitlinien/mammakarzinom (4.5.2.7).

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

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5.1.4   Tumour proliferation Labelling

Variable number: **5.1.4**

Item length: 3

Item format: Number

Definition

The data item records the expression of the immunohistochemical marker of proliferation, the Ki-67 antigen.

Rationale

This variable significantly influences tumor growth rate, and thus, represent tumoral aggressiveness.

Code examples[#]	Label	Description
0	Percentage value (%)	
…		
100	Percentage value (%)	
999	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>O'Sullivan B (ed. In chief), Brierley JD, D'Cruz AK, Fey MF, Pollock R, Vermorken JB, Huang SH (2015). Manual of Clinical Oncology. Ninth Edition. UICC. Wiley Blackwell & Sons, Ltd.

>Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF): S3-Leitlinie Früherkennung, Diagnose, Therapie und Nachsorge des Mammakarzinoms, Version 4.0, 2017 AWMF Registernummer: 032-045OL, www.leitlinienprogramm-onkologie.de/leitlinien/mammakarzinom (4.5.2.7).

Notes

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PROSTATE CANCER:
tumour related
prognostic factors

> It is not required to generate information solely for the purpose of cancer registration. Only if relevant data items have already been assessed as part of diagnosis or treatment, the findings have to be submitted to the responsible cancer registry.

5.2.1   Pretreatment Prostate Specific Antigen (PSA)

Variable number: **5.2.1**

        Item length: 5

        Item format: Number

Definition

Prostate Specific Antigen (PSA) is serine protease produced and secreted by prostate gland.

Rationale

The pretreatment serum PSA level serves as a marker in diagnosis of prostate cancer and is listed as an essential prognostic factor in TNM-8 for prostate cancer.

Code examples[#]	Label	Description
2.5		2.5 ng/ml
…		…
15.0		15.0 ng/ml
…		…
999.7	999.7 ng/ml or higher	
999.8	Test not performed	
999.9	Test result unknown	

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>N. Mottet et al. EAU - ESTRO – SIOG guidelines on prostate cancer. European Association of Urology 2016
  www.ncbi.nlm.nih.gov/pubmed

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

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5.2.2   Gleason biopsy most common grade*

Variable number: **5.2.2**

         Item length: 1

         Item format: Number

Definition

The item Gleason biopsy most common grade shows Gleason grade of the most extensive pattern (primary pattern) in biopsy-detected prostate cancer.

Rationale

Gleason score of biopsy-detected PCa comprises the Gleason grade or the most extensive (primary pattern) pattern, plus the second most common pattern (secondary pattern), if two are present, or the pattern with the highest Gleason grade, if a tumour has more than 2 histological patterns.

Code	Label	Description
1	Gleason grade 1	Well differentiated tissue.
2	Gleason grade 2	Well / moderately differentiated tissue.
3	Gleason grade 3	Moderately differentiated tissue.
4	Gleason grade 4	Poorly differentiated tissue.
5	Gleason grade 5	Undifferentiated/Anaplastic tissue.

National usage

(*****) The variable is not to be submitted to the NACR.

References

>Moch H, Humphrey PA, Ulbright TM, Reuter V. WHO Classification of Tumours of the Urinary System and Male Genital Organs. Lyon, France: International Agency for Research on Cancer; 2016.

>Epstein JI, Egevad L, Amin MB, Delahunt B, Srigley JR, Humphrey PA. The 2014 International Society of Urological Pathology (ISUP) consensus conference on Gleason grading of prostatic carcinoma: definition of grading patterns and proposal for a new grading system. Am J Surg Pathol 2016; 40:244–52.

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

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5.2.3 Gleason biopsy second most common or highest grade*

Variable number: **5.2.3**

      Item length: 1

      Item format: Number

Definition

The item Gleason biopsy second most common or highest grade shows Gleason grade of the second most common pattern (secondary pattern), or the pattern with the highest Gleason grade in biopsy-detected prostate cancer, if a tumour has more than 2 histological patterns.

Rationale

Gleason score of biopsy-detected PCa comprises the Gleason grade or the most extensive (primary pattern) pattern, plus the second most common pattern (secondary pattern), if two are present, or the pattern with the highest Gleason grade, if a tumour has more than 2 histological patterns.

Code	Label	Description
1	Gleason grade 1	Well differentiated tissue.
2	Gleason grade 2	Well / moderately differentiated tissue.
3	Gleason grade 3	Moderately differentiated tissue.
4	Gleason grade 4	Poorly differentiated tissue.
5	Gleason grade 5	Undifferentiated/Anaplastic tissue.

National usage

(*) The variable is not to be submitted to the NACR.

References

>Moch H, Humphrey PA, Ulbright TM, Reuter V. WHO Classification of Tumours of the Urinary System and Male Genital Organs. Lyon, France: International Agency for Research on Cancer; 2016.

>Epstein JI, Egevad L, Amin MB, Delahunt B, Srigley JR, Humphrey PA. The 2014 International Society of Urological Pathology (ISUP) consensus conference on Gleason grading of prostatic carcinoma: definition of grading patterns and proposal for a new grading system. Am J Surg Pathol 2016; 40:244–52.

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

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5.2.4   Gleason excision most common grade*

Variable number: **5.2.4**

      Item length: 1

      Item format: Number

Definition

The item Gleason excision most common grade shows Gleason grade of the most extensive pattern (primary pattern) in prostate cancer.

Rationale

The Gleason system is the most commonly accepted standard for prostate cancer grading and one of the most important prognostic factors for localized prostate cancer. The Gleason score of excision-detected PCa comprises the Gleason grade or the most extensive (primary pattern) pattern, plus the second most common pattern (secondary pattern), if two are present.

Code	Label	Description
1	Gleason grade 1	Well differentiated tissue.
2	Gleason grade 2	Well / moderately differentiated tissue.
3	Gleason grade 3	Moderately differentiated tissue.
4	Gleason grade 4	Poorly differentiated tissue.
5	Gleason grade 5	Undifferentiated/Anaplastic tissue.

National usage

(*) The variable is not to be submitted to the NACR.

References

>Moch H, Humphrey PA, Ulbright TM, Reuter V. WHO Classification of Tumours of the Urinary System and Male Genital Organs. Lyon, France: International Agency for Research on Cancer; 2016.

>Epstein JI, Egevad L, Amin MB, Delahunt B, Srigley JR, Humphrey PA. The 2014 International Society of Urological Pathology (ISUP) consensus conference on Gleason grading of prostatic carcinoma: definition of grading patterns and proposal for a new grading system. Am J Surg Pathol 2016; 40:244–52.

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

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5.2.5 Gleason excision second most common or highest grade*

Variable number: 5.2.5

Item length: 1

Item format: Number

Definition

The item Gleason excision second most common or highest grade shows Gleason grade of the second-most common pattern (secondary pattern) or the pattern with the highest Gleason grade in prostate cancer.

Rationale

Gleason score of excision-detected PCa comprises the Gleason grade or the most extensive (primary pattern) pattern, plus the second most common pattern (secondary pattern), if two are present.

Code	Label	Description
1	Gleason grade 1	Well differentiated tissue.
2	Gleason grade 2	Well / moderately differentiated tissue.
3	Gleason grade 3	Moderately differentiated tissue.
4	Gleason grade 4	Poorly differentiated tissue.
5	Gleason grade 5	Undifferentiated/Anaplastic tissue.

National usage

(*****) The variable is not to be submitted to the NACR.

References

>Moch H, Humphrey PA, Ulbright TM, Reuter V. WHO Classification of Tumours of the Urinary System and Male Genital Organs. Lyon, France: International Agency for Research on Cancer; 2016.

>Epstein JI, Egevad L, Amin MB, Delahunt B, Srigley JR, Humphrey PA. The 2014 International Society of Urological Pathology (ISUP) consensus conference on Gleason grading of prostatic carcinoma: definition of grading patterns and proposal for a new grading system. Am J Surg Pathol 2016; 40:244–52.

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

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5.2.6   Gleason score

Variable number: **5.2.6**

         Item length: 2

         Item format: Number

Definition

Gleason score comprises the Gleason grade or the most extensive (primary pattern) pattern, plus the second most common pattern (secondary pattern), if two are present, or the pattern with the highest Gleason grade, if a tumour has more than 2 histological patterns.

Rationale

Gleason score is the basis for prostate cancer grading and the most important essential prognostic factor.

Code	Label	Description
2	1+1	1+1 (no longer assigned on biopsy, only rarely on other specimens).
3	2+1	2+1 (no longer assigned on biopsy, only rarely on other specimens).
4	2+2	2+2 (no longer assigned on biopsy, only rarely on other specimens).
5	3+2, 2+3	3+2, 2+3 (no longer assigned on biopsy, only rarely on other specimens).
6	3+3	3+3 (in practice the lowest score).
7	3+4, 4+3	3+4, 4+3
8	4+4, 3+5, 5+3	4+4, 3+5, 5+3
9	5+4, 4+5	5+4, 4+5
10	5+5	5+5
99	Unknown	

National usage

The variable is to be submitted to the NACR.

References

>Moch H, Humphrey PA, Ulbright TM, Reuter V. WHO Classification of Tumours of the Urinary System and Male Genital Organs. Lyon, France: International Agency for Research on Cancer; 2016.

>Epstein JI, Egevad L, Amin MB, Delahunt B, Srigley JR, Humphrey PA. The 2014 International Society of Urological Pathology (ISUP) consensus conference on Gleason grading of prostatic carcinoma: definition of grading patterns and proposal for a new grading system. Am J Surg Pathol 2016; 40:244–52.

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

>Histology after surgery has priority over the biopsy, unless neoadjuvant therapy was performed prior to surgery.

5.2.7 WHO grade group

Variable number: **5.2.7**

Item length: 1

Item format: Number

Definition

A five-grade group system based on the grading categories from Gleason score 2 to 10.

Rationale

Gleason grade groups belong to the most important prognostic factors.

Code	Label	Description
1	Grade group 1	Gleason score ≤ 6 (≤ 3+3). Only individual discrete well-formed glands.
2	Grade group 2	Gleason score 7 (3 + 4). Predominantly well-formed glands with lesser component of poorly formed/fused/cribriform glands.
3	Grade group 3	Gleason score 7 (4 + 3). Predominantly poorly formed/ fused/cribriform glands with lesser component of well-formed glands.
4	Grade group 4	Gleason score 8 (4 + 4 or 3 + 5 or 5 + 3). - Only poorly formed/fused/cribriform glands or - Predominantly well-formed glands and lesser component lacking glands - Predominantly lacking glands and lesser component of well-formed glands.
5	Grade group 5	Gleason score 9-10. Lack of gland formation (or with necrosis) with or without poorly formed/fused/cribriform glands.
9	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

>Moch H, Humphrey PA, Ulbright TM, Reuter V. WHO Classification of Tumours of the Urinary System and Male Genital Organs. Lyon, France: International Agency for Research on Cancer; 2016.

>Epstein JI, Egevad L, Amin MB, Delahunt B, Srigley JR, Humphrey PA. The 2014 International Society of Urological Pathology (ISUP) consensus conference on Gleason grading of prostatic carcinoma: definition of grading patterns and proposal for a new grading system. Am J Surg Pathol 2016; 40:244–52.

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

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MELANOMA:
tumour related
prognostic factors

> It is not required to generate information solely for the purpose of cancer registration. Only if relevant data items have already been assessed as part of diagnosis or treatment, the findings have to be submitted to the responsible cancer registry.

5.3.1   Breslow thickness

Variable number: **5.3.1**

      Item length: 4

      Item format: Number

Definition

The Breslow thickness shows the distance from stratum granulosum to the deepest tumour cell, measured in mm.

Rationale

The most important prognostic factor listed in TNM-8 for Melanoma.

Code examples#	Label	Description
1.1		1.1 mm depth from stratum granulosum to the deepest tumour cell.
…		
99.9	Unknown	Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>AJCC Physician to Physician. 8th edition AJCC Melanoma Staging System. JE Gershenwald, JM Skibber University of Texas MD Anderson Cancer Center.

>Leitlinienprogramm Onkologie (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF): Diagnostik, Therapie und Nachsorge des Melanoms, Langversion 2.0, 2016, AWMF Registernummer: 032/024OL, http://leitlinienprogramm-onkologie.de/Melanom.65.0.html .

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

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COLORECTAL CANCER:
tumour related
prognostic factors

> It is not required to generate information solely for the purpose of cancer registration. Only if relevant data items have already been assessed as part of diagnosis or treatment, the findings have to be submitted to the responsible cancer registry.

5.4.1   Circumferential resection margins

Variable number: **5.4.1**

       Item length: 1

       Item format: Number

Definition

The circumferential resection margin (CRM) is a surgically created plane produced during the removal of the rectum from its surroundings.

Rationale

The information is listed as an essential prognostic factor in TNM-8 for colorectal cancer. A circumferential safety margin of less than 1 mm also significantly increases the local recurrence risk for rectal cancer.

Code	Label	Description
1	0 mm	Positive, R1
2	<1 mm	Negative, R0 "close"
3	≥1 mm	Negative, R0 "wide"
9	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

>Evidenced-based Guideline for Colorectal Cancer, long version 1.0, AWMF registration number: 021-007OL, http://leitlinienprogrammonkologie.de/Leitlinien.7.0.html.

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

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5.4.2   Microsatellite instability

Variable number: **5.4.2**

        Item length: 1

        Item format: Number

Definition

The data item records presence or absence of microsatellite instability.

Rationale

Microsatellite instability is listed as additional prognostic factor in TNM-8 for colorectal cancer. It is a pathology test that looks for a gene mutation associated with a particular type of hereditary colorectal cancer called HNPCC or Lynch syndrome. A high level of microsatellite instability is suggestive of HNPCC.

Code	Label	Description
0	No	
1	Yes	
9	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

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TESTICULAR CANCER:
tumour related
prognostic factors

> It is not required to generate information solely for the purpose of cancer registration. Only if relevant data items have already been assessed as part of diagnosis or treatment, the findings have to be submitted to the responsible cancer registry.

5.5.1   α-fetoprotein

Variable number: **5.5.1**

        Item length: 1

        Item format: Number

Definition

The data item records the serum level of the tumour marker α-fetoprotein (AFP).

Rationale

The presence of elevated α-fetoprotein (AFP) is frequent in testicular cancer, where staging is based on the determination of the anatomic extent of disease and assessment of serum tumour markers. The information is required to decide the TNM S-categories. It also helps to differentiate the histology of tumor because various germ cell tumors will show positivity for either AFP or hCG or both.

Code	Label	Description
0	AFP0	Within reference range
1	AFP1	> upper limit of reference range to < 1'000 ng/ml
2	AFP2	1'000 – 10'000 ng/ml
3	AFP3	> 10'000 ng/ml
9	AFPX	AFP not available or not performed.

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

>The reference range is provided by the testing laboratory and varies due to testing equipment, chemical reagents, and analytical techniques.

5.5.2   β-hCG

Variable number: **5.5.2**

        Item length: 1

        Item format: Number

Definition

The data item records the level of serum tumour marker human chorionic gonadotropin (β-hCG).

Rationale

The presence of elevated human chorionic gonadotropin (β-hCG) is frequent in testicular cancer, where staging is based on the determination of the anatomic extent of disease and assessment of serum tumour markers. The information is required to decide the TNM S-categories. It also helps to differentiate the histology of tumor because various germ cell tumors will show positivity for either AFP or hCG or both.

Code	Label	Description
0	hCG0	Within reference range
1	hCG1	> upper limit of reference range if upper limit < 5'000 mIU/ml
2	hCG2	5'000 – 50'000 mIU/ml
3	hCG3	> 50'000 mIU/ml
9	hCGX	hCG not available or not performed.

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

>The reference range is provided by the testing laboratory and varies due to testing equipment, chemical reagents, and analytical techniques.

5.5.3   LDH

Variable number: **5.5.3**

       Item length: 1

       Item format: Number

Definition

The data item records the levels of serum tumour marker lactate dehydrogenase (LDH).

Rationale

The presence of elevated lactate dehydrogenase (LDH) is frequent in testicular cancer, where staging is based on the determination of the anatomic extent of disease and assessment of serum tumour markers. The information is required to decide the TNM S-categories.

Code	Label	Description
0	LDH0	Within reference range
1	LDH1	> upper limit of reference range if upper limit < 1.5 x N$^{\#}$
2	LDH2	1.5 – 10 x N$^{\#}$
3	LDH3	> 10 x N$^{\#}$
9	LDHX	LDH not available or not performed.

\#: N indicates the upper limit of normal for the LDH assay.

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

>The reference range is provided by the testing laboratory and varies due to testing equipment, chemical reagents, and analytical techniques.

5.5.4   Serum tumour markers

Variable number: **5.5.4**

       Item length: 1

       Item format: Number

Definition

The data item records the TNM S-categories as combination of levels for AFP, hCG, and LDH.

Rationale

Essential for TNM prognostic staging of testicular cancer.

Code	Label	Description
0	S0	Serum marker study levels within normal limits.
1	S1	
2	S2	
3	S3	
9	SX	Serum marker studies not available or not performed.

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

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HEAD/NECK CANCER:
tumour related
prognostic factors

> It is not required to generate information solely for the purpose of cancer registration. Only if relevant data items have already been assessed as part of diagnosis or treatment, the findings have to be submitted to the responsible cancer registry.

5.6.1 HPV/p16

Variable number: **5.6.1**

    Item length: 1

    Item format: Number

Definition

HPV (Human papillomavirus) positivity is defined as showing either evidence of HPV gene expression (tested with p16 immunohistochemistry) or HPV DNA, or both.

Rationale

This information is an essential prognostic factor of squamous cell carcinoma with cervical lymph node metastases without an identified primary carcinoma, and in oropharyngeal cancer.

Code	Label	Description
0	No	HPV- or p16- negative
1	Yes	HPV- or p16- positive
9	Unknown	Not stated / Not assessed.

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

>HPV status information is only mandatory for squamous cell carcinoma with cervical lymph node metastases without an identified primary carcinoma, and in oropharyngeal cancer.

5.6.2   EBV

Variable number: **5.6.2**

       Item length: 1

       Item format: Number

Definition

EBV (Epstein Barr virus) positivity is defined as showing evidence of EBV antigen in a blood test, or EBV DNA or RNA by polymerase chain reaction.

Rationale

This information is an essential prognostic factor of squamous cell carcinoma with cervical lymph node metastases without an identified primary carcinoma.

Code	Label	Description
0	No	EBV- negative.
1	Yes	EBV- positive.
9	Unknown	Not stated/not assessed.

National usage

The variable is to be submitted to the NACR.

References

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

Notes

>EBV status information is only mandatory for squamous cell carcinoma with cervical lymph node metastases without an identified primary carcinoma.

TREATMENT:
prognostic factors
related to treatment

> It is not required to generate information solely for the purpose of cancer registration. Only if relevant data items have already been assessed as part of diagnosis or treatment, the findings have to be submitted to the responsible cancer registry.

6.1   Residual invasive tumour

Variable number: **6.1**

     Item length: 1

     Item format: Number

Definition

This data items records the invasive tumour status after treatment. The R classification can be used following surgical treatment alone, after radiotherapy alone, after chemotherapy alone or following multimodal therapy. The status after treatment takes distant metastases into account.

Rationale

This information is a strong indicator of prognosis and reflects the effect of treatment.

Code	Label	Description
0	R0	No residual tumour detectable by any diagnostic means. In M1 cases, the distant metastasis as well as the primary tumour must be removed completely.
1	R1	Microscopic residual tumour.
2	R2	Macroscopic residual tumour.
8	RX	Presence of residual tumour cannot be assessed.
9	Unknown	There is no information on the presence or absence of residual tumour.

National usage

The variable is to be submitted to the NACR.

References

>Wittekind, Compton, Greene, Sobin etc.: TNM Residual Tumor Classification Revisited. Cancer. 2002; 94: 2511-2516.

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5th Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

Notes

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6.2   Residual in-situ tumour

Variable number: **6.2**

         Item length: 1

         Item format: Number

Definition

This data items records the in-situ tumour status after treatment. The R classification can be used following surgical treatment alone, after radiotherapy alone, after chemotherapy alone or following multimodal therapy. The status after treatment takes distant metastases into account.

Rationale

This information is a strong indicator of prognosis and reflects the effect of treatment.

Code	Label	Description
0	R0	No residual tumour detectable by any diagnostic means. In M1 cases, the distant metastasis as well as the primary tumour must be removed completely.
1	R1	Microscopic residual tumour.
2	R2	Macroscopic residual tumour.
8	RX	Presence of residual tumour cannot be assessed.
9	Unknown	There is no information on the presence or absence of residual tumour.

National usage

The variable is to be submitted to the NACR.

References

> Wittekind, Compton, Greene, Sobin etc.: TNM Residual Tumor Classification Revisited. Cancer. 2002; 94: 2511-2516.

>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.

>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.

>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 5th Edition. 1997 by Wiley-Liss, Inc. ISBN 3-540-63373-1.

Notes

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6.3   Resection margin invasive tumour

Variable number: **6.3**

      Item length: 4

      Item format: Number

Definition

The data item indicates the minimal width of the normal tissue between the tumour and the surgical margin of the resected tumour on primary site (microscopic distance between the outermost tumour cells and the cut edge of the specimen). Measurement in m140illimetre.

Rationale

Most reliable parameter to infer that the patient is free from detectable tumour cells. It is recommended as an essential tumour-related prognostic factor in cancer of oral cavity or breast by UICC TNM-8.

Code examples[#]	Description
0.0	There are invasive tumour cells in the resection margin.
0.1	There is 0.1 mm margin between invasive tumour and the cut edge of the specimen.
…	
1.0	There is 1.0 mm margin between invasive tumour and the cut edge of the specimen.
…	
98.0	Not applicable
99.0	Unknown. Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

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Notes

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6.4   Resection margin in-situ tumour

Variable number: **6.4**

      Item length: 4

      Item format: Number

Definition

The data item indicates the minimal width of the normal tissue between the tumour and the surgical margin of the resected tumour on primary site (microscopic distance between the outermost tumour cells and the cut edge of the specimen). Measurement in 141illimetre.

Rationale

This information is the most reliable parameter to infer that the patient is free from detectable tumour cells. It is recommended as an essential tumour-related prognostic factor in cancer of oral cavity or breast by UICC TNM-8.

Code examples[#]	Description
0.0	There are in-situ tumour cells in the resection margin.
0.1	There is 0.1 mm margin between in-situ tumour and the cut edge of the specimen.
…	
1.0	There is 1.0 mm margin between in-situ tumour and the cut edge of the specimen.
…	
98.0	Not applicable
99.0	Unknown. Not stated / Not assessed.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

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Notes

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6.5 Sentinel lymph node assessment

Variable number: **6.5**

Item length: 1

Item format: Number

Definition

The data item indicates whether the sentinel lymph node is excised and the result of the examination. The sentinel lymph node is the first lymph node to receive lymphatic drainage from a primary tumour.

Rationale

This information is used to evaluate the quality of diagnostic procedures and to assess the impact of sentinel lymph node procedures on outcome.

Code	Label	Description
0	N0	Sentinel lymph node not involved.
1	N1	Sentinel lymph node involved.
8	NX	Sentinel lymph node cannot be assessed.
9	Unknown	No information in the patient's reports.

National usage

The variable is to be submitted to the NACR.

References

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Notes

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6.6   Number of examined sentinel lymph nodes

Variable number: **6.6**

       Item length: 2

       Item format: Number

Definition

The data item records the total number of sentinel lymph nodes that were excised and examined by the pathologist.

Rationale

This information is used to evaluate the quality of diagnostic procedures and to assess the impact of sentinel lymph node procedures on outcome.

Code examples[#]	Label	Description
0	None	No sentinel lymph node excised.
1	1 node	One sentinel lymph node excised.
…	…	
96	96 nodes	Ninety-six sentinel lymph nodes excised.
97	97 nodes or more	Ninety-seven or more sentinel lymph nodes excised.
98	Number not exactly known.	Sentinel lymph nodes were excised, but no information on the number.
99	Unknown	No information whether sentinel lymph nodes were excised or not.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

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Notes

>Register the lower limit x if "x or more were excised" is reported.

6.7   Number of positive sentinel lymph nodes

Variable number: **6.7**

       Item length: 2

       Item format: Number

Definition

The data item records the number of sentinel lymph nodes examined by the pathologist and found to contain metastases.

Rationale

This information is used to evaluate the quality of diagnostic procedures and to assess the impact of sentinel lymph node procedures on outcome.

Code examples[#]	Label	Description
0	None	No sentinel lymph node invaded.
1	1 node	One sentinel lymph node invaded.
…	…	
96	96 nodes	Ninety-six sentinel lymph nodes invaded.
97	97 nodes or more	Ninety-seven or more sentinel lymph nodes invaded.
98	Number not exactly known.	Sentinel lymph nodes were invaded, but no information on the number.
99	Unknown	No information whether sentinel lymph nodes were invaded or not.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

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Notes

>Register the lower limit x if "x or more were invaded" is reported.

FIRST TREATMENT COMPLEX

- The first treatment complex consists of all treatments planned after the diagnosis, incl. watchful waiting.
- It is not required to generate information solely for the purpose of cancer registration. Only if relevant data items have already been assessed as part of diagnosis or treatment, the findings have to be submitted to the responsible cancer registry.

7.1 Basis of first treatment complex decision

Variable number: 7.1

Item length: 1

Item format: Number

Definition

This data item records the basis of treatment decision for the entire first treatment complex. The first treatment complex includes all therapy steps planned after the diagnosis. In most cases the decision for the first treatment complex is discussed and agreed at multidisciplinary tumour boards. A tumour board is an interdisciplinary medical committee that develops an individual treatment plan for patients with a malignant disease.

Rationale

The information serves to evaluate the treatment quality.

Code	Label	Description
1	Tumour board	An interdisciplinary medical committee.
2	Other (not specified)	Not a tumour board.
9	Unknown	The basis of treatment decision is unknown.

National usage

The variable is to be submitted to the NACR.

References

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Notes

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7.2.1 Date of first treatment complex decision

Variable number: **7.2.1**

     Item length: 10

     Item format: Date (dd.mm.yyyy)

Definition

This data item records the date when the treatment decision was made. To be recorded for the entire first treatment complex.

Rationale

This information is used to evaluate treatment quality.

Code examples[#]	Description
01.01.2005	Note: for single digit day or month, record with a leading 0.
15.01.2005	Note: if exact day unknown, set day as 15th of the respective month.
30.06.2005	Note: if exact day and month unknown, set date as 30th of June of the respective year.
...	

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR in truncated form, with day set to unknown (i.e. 15) for all cases. In addition, the accompanying age in days is to be submitted to the NACR.

References

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Notes

>If the treatment decisions were made in more than one tumourboard, the date of the first tumourboard is recorded.

7.2.2   Accuracy for date of 1ˢᵗ treatment complex decision

Variable number: **7.2.2**

    Item length: 1

    Item format: Number

Definition

The data item indicates the accuracy of the date when the treatment decision was made.

Rationale

The data item is used to identify groups of patients where ages or time periods are not known with certainty (e.g. for sensitivity analyses).

Code	Label	Description
0	Exact date	All date components are known.
1	Day uncertain	The day in date is imputed.
2	Day/Month uncertain	The day and month in date are imputed.
3	Estimated date	All date components are imputed.

National usage

The variable is to be submitted to the NACR.

References

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Notes

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7.3 First treatment complex goal(s)

Variable number: **7.3**

Item length: 1

Item format: Number

Definition

The data item records the goal for each treatment as part of the first treatment complex.

Rationale

Quality assessment of treatment patterns depends on the goal of the first treatment complex.

Code	Label	Description
1	Curative	A treatment approach with the aim to remove the tumour, rid the body of wandering cancer cells, and prevent a recurrence.
2	Palliative	The purpose of palliative treatment is to relieve the symptoms and to improve quality of life in cases, when curative treatment is impossible
9	Unknown	Not stated.

National usage

The variable is to be submitted to the NACR.

References

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Notes

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7.4 First treatment complex code(s)

Variable number: **7.4**

    Item length: 10

    Item format: Alphanumeric

Definition

The data item records the CHOP code, or NACR-assigned CHOP-like code for treatments where no CHOP code exists, for each treatment as part of the first treatment complex. CHOP is Swiss classification of surgical operations and other diagnostic and treatment procedures and interventions.

Rationale

This information is readily available at the sources (clinics, physicians) in standardized and updated form. Treatment indicators at the system level will be compared with evidence-based guidelines.

Code examples[#]	Label	Description
85.21	Local excision of a lesion on the breast	CHOP procedure code used by Swiss treatment institutions.
85.45.00	Radical mastectomy, not otherwise specified	CHOP procedure code used by Swiss treatment institutions.
…	…	
99.2R.01	Hormontherapy, NOS	CHOP-like code created for cancer registration use only.
998	No treatments planned	CHOP-like code created for cancer registration use only.
…	…	
999	Unknown	No information in patients records.

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

Notes

-

7.5.1 First treatment complex start date(s)

Variable number: **7.5.1**

Item length: 10

Item format: Date (dd.mm.yyyy)

Definition

The data item records the dates when each treatment of the first treatment complex has been started.

Rationale

This information is used to evaluate treatment quality. It is important to measure the delay between diagnosis and treatment, as well as the time intervals between treatments, and between treatment and recurrence.

Code examples[#]	Description
01.01.2005	Note: for single digit day or month, record with a leading 0.
15.01.2005	Note: if exact day unknown, set day as 15th of the respective month.
30.06.2005	Note: if exact day and month unknown, set date as 30th of June of the respective year.
…	

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR in truncated form, with day set to unknown (i.e. 15) for all cases. In addition, the accompanying age in days is to be submitted to the NACR.

References

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Notes

-

7.5.2 Accuracy for date(s) of 1st treatment complex start

Variable number: **7.5.2**

      Item length: 1

      Item format: Number

Definition

Indicates the accuracy of the date(s) when each treatment of the first treatment complex has been started.

Rationale

The data item is used to identify groups of patients where ages or time periods are not known with certainty (e.g. for sensitivity analyses).

Code	Label	Description
0	Exact date	All date components are known.
1	Day uncertain	The day in date is imputed.
2	Day/Month uncertain	The day and month in date are imputed.
3	Estimated date	All date components are imputed.

National usage

The variable is to be submitted to the NACR.

References

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Notes

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7.6 First treatment complex institution(s)*

Variable number: **7.6**

Item length: 255

Item format: Text

Definition

The data item records the name and address of the person and institution responsible for treatment.

Rationale

This information allows providing quality feedback to those institutions requesting it. It also allows regional and national statistical reports on the relative contribution of different types of institutions treating cancer patients.

National usage

(*) The variable is not to be submitted to the NACR.

References

>Medical practices: GLN (Global Location Number) www.refdata.ch/de/weitere-leistungen/swiss-rx-login

>Hospitals: official hospital lists www.bag.admin.ch/bag/de/home/zahlen-und-statistiken/zahlen-fakten-zu-spitaelern/spital-suchen.

Notes

>Addresses will be taken from national uniform lists of health service providers.

>Metadata for the institution responsible for treatment can also be registered to facilitate the exchange of information.

>The cancer registries define, and update on a regular basis, the official address of all responsible persons and hospital units submitting cancer information.

>Multiple persons or institutions may optionally be registered per diagnosis.

COURSE OF DISEASE:

Recurrences/Transformations

> It is not required to generate information solely for the purpose of cancer registration. Only if relevant data items have already been assessed as part of diagnosis or treatment, the findings have to be submitted to the responsible cancer registry.

8.1 Type of recurrence(s)/transformation(s)

Variable number: 8.1

   Item length: 1

   Item format: Number

Definition

The data item records the type of first recurrence of the disease or the occurrence of a transformation.

Rationale

The information is required for the analysis of progression free survival and disease-free survival.

Code	Label	Description
1	Progression	Locoregional[#] new findings without disease free intermission. For example: the tumour that is still present starts to progress after a period of stabilisation. The international reporting rules for multiple primaries have to be applied for registration (reference below).
2	Transformation	The development of one ICD-O M term into another (for example, the change of a haematopoetic or lymphoid neoplasm from chronic to acute phase). In order to decide on haematological transformation event, adherence to the ENCR recommendation and Haemacare guideline, cited below, is mandatory.
3	Metastasis	New finding at a site distant to the primary tumour, i.e. metachronous metastasis. Either with or without disease free intermission.
4	Relapse	Locoregional[#] new findings after a period of documented disease-free intermission or remission without detectable tumour. The international reporting rules for multiple primaries have to be applied for registration (reference below).
9	Unknown P/R	Insufficient information to differentiate between Progression and Relapse.

#: Locoregional refers to the same or adjacent site of the original tumour or the regional lymph nodes. A list of those lymph nodes defined as regional lymph nodes for each cancer site can be found in the TNM Classification of Malignant Tumours International Union Against Cancer (UICC).

National usage

The variable is to be submitted to the NACR.

References

>European Network of Cancer Registries (ENCR): Recommendations for Registration of Haematological Malignancies (2014). www.encr.eu/sites/default/files/pdf/ENCR_Haematological_Malignancies_Summary_Recommendations_Feb_2014.pdf [last access 8.2.2019].

>Gavin, A et al. Towards optimal clinical and epidemiological registration of haematological malignancies: Guidelines for recording progressions, transformations and multiple diagnoses. *European Journal of Cancer* **51** (2015), 1109–1122.

>Haemacare Guideline: Sant M, et al. Manual for Coding and Reporting Haematological Malignancies. Tumori 96(4), (2010).

> International rules for multiple primary cancers (ICD-0 third edition). Eur J Cancer Prev. 2005; 14(4):307–308. https://www.encr.eu/sites/default/files/pdf/MPrules_july2004.pdf [last access 29.6.2021].

Notes

\>More than a single event may be registered per diagnosis.

8.2.1 Date of recurrence(s)/transformation(s)

Variable number: **8.2.1**

　Item length: 10

　Item format: Date (dd.mm.yyyy)

Definition

The data item records the date of the recurrent event or transformation.

Rationale

The information is required for the analysis of progression free survival and disease-free survival.

Code examples#	Description
01.01.2005	Note: for single digit day or month, record with a leading 0
15.01.2005	Note: if exact day unknown, set day as 15th of the respective month.
30.06.2005	Note: if exact day and month unknown, set date as 30th of June of the respective year.
…	

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to **t**he NACR in truncated form, with day set to unknown (i.e. 15) for all cases. In addition, the accompanying age in days is to be submitted to the NACR.

References

-

Notes

-

8.2.2   Accuracy for date of event(s)

Variable number: **8.2.2**

    Item length: 1

    Item format: Number

Definition

Indicates the accuracy of the date of the recurrent event or transformation.

Rationale

The data item is used to identify groups of patients where ages or time periods are not known with certainty (e.g. for sensitivity analyses).

Code	Label	Description
0	Exact date	All date components are known.
1	Day uncertain	The day in date is imputed.
2	Day/Month uncertain	The day and month in date are imputed.
3	Estimated date	All date components are imputed.

National usage

The variable is to be submitted to the NACR.

References

-

Notes

-

8.3 Event ICD-O version

Variable number: **8.3**

Item length: 2

Item format: Number

Definition

This data item records the version of the International Classification of Diseases for Oncology (ICD-O) used to code the recurrence or transformation. Adherence to the ENCR recommendation and Haemacare guideline, cited below, is mandatory.

Rationale

The International Classification of Diseases for Oncology (ICD-O) is regularly updated to include the progress in medical knowledge.

Code	Label	Description
10	Version 1	
20	Version 2	
30	Version 3.0	WHO 2000
31	Version 3.1	Update 2011
32	Version 3.2	Update 2019

National usage

The variable is to be submitted to the NACR.

References

>ICD-O: http://codes.iarc.fr/abouticdo.php

>European Network of Cancer Registries (ENCR): Recommendations for Registration of Haematological Malignancies (2014).
www.encr.eu/sites/default/files/pdf/ENCR_Haematological_Malignancies_Summary_Recommendations_Feb_2014.pdf [last access 8.2.2019].

>Gavin, A et al. Towards optimal clinical and epidemiological registration of haematological malignancies: Guidelines for recording progressions, transformations and multiple diagnoses. *European Journal of Cancer* **51** (2015), 1109–1122.

>Haemacare Guideline: Sant M, et al. Manual for Coding and Reporting Haematological Malignancies. *Tumori* **96**(4), (2010).

Notes

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8.4 Morphology term before change of main diagnosis*

Variable number: **8.4**

    Item length: 6

    Item format: Alphanumeric

Definition

The data item records the morphology according to ICD-O in the case that the main diagnosis has been changed (e.g. because the later diagnosis was within three months after the first). Adherence to the ENCR recommendation and Haemacare guideline, cited below, is mandatory.

Rationale

This information allows to retain the earlier morphology code.

Code examples[#]	Label
9940/3	Hairy cell leukaemia
…	

#: only examples are shown to reduce table size

National usage

(*) The variable is not to be submitted to the NACR.

References

>European Network of Cancer Registries (ENCR): Recommendations for Registration of Haematological Malignancies (2014).
www.encr.eu/sites/default/files/pdf/ENCR_Haematological_Malignancies_Summary_Recommendations_Feb_2014.pdf [last access 8.2.2019].

>Gavin, A et al. Towards optimal clinical and epidemiological registration of haematological malignancies: Guidelines for recording progressions, transformations and multiple diagnoses. *European Journal of Cancer* **51** (2015), 1109–1122.

>Haemacare Guideline: Sant M, et al. Manual for Coding and Reporting Haematological Malignancies. *Tumori* **96**(4), (2010).

Notes

>If there was no change of the main diagnosis, this variable remains empty.

8.5   Morphology term after Transformation

Variable number: **8.5**

       Item length: 6

       Item format: Alphanumeric

Definition

The data item records the morphology term according to ICD-O after transformation. For haematological transformations, adherence to the ENCR recommendation and Haemacare guideline, cited below, is mandatory.

Rationale

This information allows the study how the risk of certain transformations varies over time since diagnosis, as a function of treatment, patient, and tumour characteristics.

The table provides two typical examples from clinical practice: first a haematological M term after transformation, and secondly a brain tumour M term after transformation.

Code examples[#]	Label	Description
9801/3	Acute leukemia, NOS	For example: as a transformation from M9945/3 (Chronic myelomonocytic leukaemia).
9390/1	Atypical choroid plexus papilloma	For example: as a transformation from M9390/0 (Choroid plexus papilloma, NOS).
…		

#: only examples are shown to reduce table size

National usage

The variable is to be submitted to the NACR.

References

>European Network of Cancer Registries (ENCR): Recommendations for Registration of Haematological Malignancies (2014).
www.encr.eu/sites/default/files/pdf/ENCR_Haematological_Malignancies_Summary_Recommendations_Feb_2014.pdf [last access 8.2.2019].

>Gavin, A et al. Towards optimal clinical and epidemiological registration of haematological malignancies: Guidelines for recording progressions, transformations and multiple diagnoses. *European Journal of Cancer* **51** (2015), 1109–1122.

>Haemacare Guideline: Sant M, et al. Manual for Coding and Reporting Haematological Malignancies. *Tumori* **96**(4), (2010).

Notes

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8.6 Topography(s) of post-diagnosis metastases

Variable number: **8.6**
      Item length: 2
      Item format: Number

Definition
The data item identifies the distant site(s) of metastatic involvement after disease recurrence.

Rationale
This information allows the study how the risk of distant metastasis varies over time since diagnosis, as a function of treatment, patient, and tumour characteristics.

Code	Label	Description
1	PUL	Pulmonary (C34).
2	OSS	Osseous (C40, 41).
3	HEP	Hepatic (C22).
4	BRA	Brain (C71).
5	LYM	Lymph nodes (C77).
6	MAR	Bone marrow (C42.1).
7	PLE	Pleura (C38.4).
8	PER	Peritoneum (C48.1, 2).
9	ADR	Adrenals (C74).
10	SKI	Skin (C44).
11	OTH	Others.
99	UNK	No information on the topography of metastases available, e.g. poly-metastatic disease.

National usage
The variable is to be submitted to the NACR.

References
>Brierley, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 8th Edition. 2017 by John Wiley & Sons. ISBN 978-3-527-34280-8.
>Wittekind, Compton, Brierley, Sobin (eds.): UICC TNM Supplement. A Commentary on Uniform use, 4th Edition. 2012 by John Wiley & Sons. ISBN 978-1-4443-3243-8.
>Sobin, Gospodarowicz, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 7th Edition. 2010 by John Wiley & Sons. ISBN 978-1-4443-3241-4.
>Sobin, Wittekind (eds.): UICC TNM Classification of Malignant Tumours, 6th Edition. 2002 by Wiley-Liss Inc. ISBN 0-471-22288-7.

Notes
>If the patient has multiple metastases, more than one topography is registered.

APPENDIX

Changes made between version 1.0 and 1.1

Item / No / Page	Changes as of 15.10.2019
Titelpage	A new logo for the NACR has been created and replaces the NICER logo.
Acknowledgement / p1	Added page.
Abbreviations / p8	Added NACR National Agency for Cancer Registration and NICER National Institute for Cancer Epidemiology and Registration
Case definitions /p9	Added text in Footnote 1: "431.112.1" after Ordinance. Added text in Footnote 3: "Verification refers to medically accepted diagnostic procedures (clinical, cytological, histological, laboratory test)."
Sex / 1.2 / p13	Format «Numeric» changed with "Number"
Civil status / 1.12 / p26	Description of anulled marriage translated to English: "The civil status "Anulled marriage" can arise because the last marriage has been declared invalid or because the last spouse has been declared a missing person."
Date of notification / 2.2 / p39	Added Note: "Based on practical considerations, the date of case creation in the registration software may be used."
Diagnostic method(s) used / 2.8 / p46-47	Deleted "*" after Variable name. Deleted text in Definition: "…optional…". Inserted new level 23: "Biopsy locoregional or of metastasis" Deleted text in National usage: "…not…" Deleted text in Notes: "This variable is optional." Added text in Notes: "Data providers can either report diagnostic method(s) individually, or submit already existing reports, which contain such information. The reported information must include the method with the highest validity, according to the data providers' knowledge. Variable 2.7 (Most valid basis of diagnosis) informs about different levels of validity."
Diagnostic institutions(s) / 2.9 / p48	Deleted text in Notes: "responsible ~~persons and~~ hospital units"
Case Number / 2.11/ p50	Reduced Item length from 11 to 10.
Laterality / 3.8 / p60	Deleted text in Description of code 9 (Unknown): "…the origin of the cancer was on the left or right side of the body." New text in Description of code 9 (Unknown): "…the reportable cancer was unilateral or bilateral."
ICCC-3 main group / 3.9.1 / p61	Added Note: "Among benign and borderline tumours, only those of the CNS should be classified according to ICCC-3 (Main group III and subgroup Xa)."

ICCC-3 code / 3.9.2 / p62	Added Note: "Among benign and borderline tumours, only those of the CNS should be classified according to ICCC-3 (Main group III and subgroup Xa)."
COG staging / 4.19 / p83	Added Note: "For Toronto staging do not use Stage V for bilateral tumours, but stage the kidney with the more advanced disease."
COG ALL staging / 4.20 / p84	Deleted redundant text in Definition: "…fluid…"
FIGO staging / 4.21 / p85	Added Note: "FIGO stage requires known UICC TNM version."
IRSS staging / 4.23 / p87	Added text to Description of code 0: "The tumour is confined to the globe. Enucleation has not been performed." Added letters to codes: "p", "c" Deleted text to Description of code pI: "…, with negative margins (R0)." Added text to Description of code pI: "…, completely resected histologically." Deleted text to Description of code cIVa.1: "Metastatic disease." Added text to Description of code cIVa.1: "Haematogenous metastasis (without CNS involvement): single lesion." Two references added: ">Chantada G, Sampor C, Bosaleh A et al. Comparison of Staging Systems for Extraocular Retinoblastoma JAMA Ophthalmol 2013: doi:10.1001/jamaophthalmol.2013.260. >Fabian ID, Reddy A, and SagooMS Classification and staging of retinoblastoma Community Eye Health 2018 31: 11-13."
PRETEXT staging / 4.25 / p89	Deleted code, label and description: "C1; C1; Additional criteria: Tumour involving the caudate lobe."
Rhabdomyosarcoma site staging / 4.28 / p92	Deleted text in description to code I: "Organ confined, low-grade." Added text in description to code I: "Any T, Any N, M0, Favourable Site."
SIOP staging / 4.31 / p95	Extended Note: "…use Children's Oncology Group (COG) /National Wilms Tumour Study Group (NWTSG) staging (Variable 4.19)." Added Note: "For Toronto staging do not use Stage V for bilateral tumours but stage the kidney with the more advanced disease."
St. Jude/Murphy staging / 4.32 / p96	New description for code I: "Involvement of a single tumour mass or nodal area, excluding the mediastinum and abdomen."
Toronto Tier II staging / 4.33.1 / p97-98	Old table of code examples removed. New table added: | Disease	Staging system	Code examples#
---	---	---
Acute lymphoblastic leukaemia	COG ALL	CNS1
Acute myeloid leukaemia	Toronto	CNS positive
Hodgkin lymphoma	Ann-Arbor	stage IA/B
Non-Hodgkin lymphoma	St. Jude/Murphy	stage I	

	Neuroblastoma	INRGSS	L1	
	Wilms tumour	COG	Stage I	
	Wilms tumour	SIOP	Stage y-I	
	Rhabdomyosarcoma, non-rhabdomatous soft tissue sarcoma	TNM	TNM stage 1	
	Retinoblastoma	IRSS	Stage 0	
	Hepatoblastoma	PRETEXT	I	
	Testicular cancer	TNM	TNM stage I	
	Ovarian cancer	FIGO	FIGO stage I	
	All diseases	No information available.	99	
	#: only examples are shown to reduce table size			
	Added Note: "See the individual staging systems for further details."			
Toronto Tier II (manual) staging / 4.33.2 / p99	Added text to Rationale: "…ependymomas…" Added text to Rationale: "…as well as Ewings's sarcoma and osteosarcoma." Deleted label text to code M3: "Metastatic" Deleted description for code M3: "Used for medulloblastoma with macroscopic spinal metastases at diagnosis." New description for code M3: "Visible metastasis in spine or visible metastasis in cervicomedullary (junction)." Added text to description of code Metastatic: "…or osteosarcoma…".			
SalzerKuntschik grading system / 4.36 / p102	Old labels R1 to R6 replaced with new labels: "I, II, III, IV, V, VI"			
Shimada grading system / 4.37 / p103	Changed text in description of code 2 Age 1.5-5.0 yrs: "1) Undifferentiated and/or high MKI tumour 2) poorly differentiated and/or intermediate MKI tumour." Two references added: ">Shimada H, Chatten J, Newton WA, et al. Histopathologic prognostic factors in neuroblastic tumours: definition of subtypes of ganglioneuroblastoma and an age-linked classification of neuroblastomas. J Natl Cancer Inst 1984; 73:405–16. >Shimada H, Umehara S, Monobe Y et al. International neuroblastoma pathology classification for prognostic evaluation of patients with peripheral neuroblastic tumours: a report from the Children's Cancer Group Cancer 2001; 92:2451-61."			
Topography of metastases at diagnosis / 4.42 / p108	Added text to the description of code 99 (Unk): "…, e.g. poly-metastatic disease."			
Oestrogen receptor status / 5.1.1 / p110	Added Note: "If both, quantitative and qualitative information is known, the quantitative is to be reported."			
Progesterone receptor status / 5.1.2 / p111	Added Note: "If both, quantitative and qualitative information is known, the quantitative is to be reported."			
Titelpage FIRST TREATMENT COMPLEX / p143	Deleted text in line 3: "Registration is restricted to treatments actually applied."			

Basis of first treatment complex decision / 7.1 / p144	Deleted text in Definition: "…initial treatment…". Added text in Definition: "…first treatment complex…"
First treatment complex goal(s) / 7.3 / p147	Deleted Note: "Planned but not applied treatments are not registered."
First treatment complex code(s) / 7.4 / p148	Code example 99.2R.01 text deleted: "(preliminary code)" and in description: "[Note: preliminary coding is still under discussion]" Code example 99.9R.00 (Watchful waiting) deleted. Added example code 998 and Label: "No treatments planned" Added text in Description for code 999: "No information in patients records." Deleted Note: "Planned but not applied treatments are not registered."
Type of event(s) / 8.1 / p153	New code, label, and description added: "9; Unknown P/R; Insufficient information to differentiate between Progression and Relapse."
Topography of post-diagnosis metastases / 8.6 / p159	Added text to the description of code 99 (Unk): "…, e.g. poly-metastatic disease."
Type of recurrence(s), transformation(s) / 8.1 / p153	Added level 9: Unknown P/R

Changes made between version 1.1 and 1.2

Item / No / Page	Changes as of 01.03.2022
Title / p1	V 1.1 to V 1.2 changed.
CASE DEFINITIONS / Reportable diagnosed neoplasms / p9	For "All carcinoma in-situ" "[except D04 «Carcinoma in situ of skin» in Adults] added."
FSO City/Municipality number/ 1.9 / p23	References: ">FSO: www.bfs.admin.ch/bfsstatic/dam/assets/4242620/master [last access: 27.11.2018]" changed to ">https://www.cadastre.ch/de/services/service/registry/plz.html".
Place of birth/ 1.10 / p2	References: ">FSO: www.bfs.admin.ch/bfsstatic/dam/assets/4242620/master [last access: 27.11.2018]" changed to ">https://www.cadastre.ch/de/services/service/registry/plz.html".
ICD-O Histological grade / 3.7 / p59	Code 1 Description: "Nucleoli that are inconspicuous and basophilic at ×400 magnification" added.
ICD-O Histological grade / 3.7 / p59	Code 2 Description: "Nucleoli that are clearly visible at ×400 magnification and eosinophilic" added.
ICD-O Histological grade / 3.7 / p59	Code 3 Description: "Clearly visible nucleoli at ×100 magnification." added.
ICD-O Histological grade / 3.7 / p59	Code 4 Description: "Nucleoli with extreme pleomorphism or rhabdoid and/or sarcomatoid morphology" added.
ICD-O Histological grade / 3.7 / p59	Notes:" >The WHO/ISUP grading for clear cell renal cell carcinoma and papillary renal cell carcinoma is based on the evaluation of nucleoli. Grades one to four are to be used for cases with ICD-O C64, M8310/3, M8260/3" added.
Number of involved regional lymph nodes / 4.11 / p75	New code 998 added.
Number of involved regional lymph nodes / 4.11 / p75	Notes: ">Register the lower limit x if "x or more were invaded" is reported" added.
Number of examined regional lymph nodes / 4.12 / p76	New code 998 added.
Number of examined regional lymph nodes / 4.12 / p76	Notes: ">Register the lower limit x if "x or more were invaded" is reported" added.

IRSS staging / 4.23 / p87	New code 0 (A) added.
Clinical tumour size / 4.39 / p106	Notes: Text ">Use code "1" if tumour diameter or the largest extension is provided with precision of one decimal place, and if diameter ≥0.1 and ≤0.9 mm. Round to the nearest integer if diameter >1.0. >0 mm is not a valid code (e.g. in the case of CUP). The variable is left empty." added
Pathological tumour size / 4.40 / p107	Notes: Text ">If tumor size is given in tenths of millimeters, record size as 001 if largest dimension or diameter of tumor is between 0.1 and 0.9 mm. If the size is larger than 1.0 mm, round to the nearest integer" replaced by ">Use code "1" if tumour diameter or the largest extension is provided with precision of one decimal place, and if diameter ≥0.1 and ≤0.9 mm. Round to the nearest integer if diameter >1.0. >0 mm is not a valid code (e.g. after neoadjuvant therapy). The variable is left empty"
Number of examined sentinel lymph nodes / 6.6 / p142	New code 98 added.
Number of examined sentinel lymph nodes / 6.6 / p142	Notes: ">Register the lower limit x if "x or more were invaded" is reported" added.
Number of positive sentinel lymph nodes / 6.7 / p143	New code 98 added.
Number of positive sentinel lymph nodes / 6.7 / p143	Notes: ">Register the lower limit x if "x or more were invaded" is reported" added.
Type of recurrence(s)/transformation(s) / 8.1 / p154	Code 1: "The international reporting rules for multiple primaries have to be applied for registration (reference below)" added.
Type of recurrence(s)/transformation(s) / 8.1 / p154	Code 4: "The international reporting rules for multiple primaries have to be applied for registration (reference below)" added.
Type of recurrence(s)/transformation(s) / 8.1 / p154	New references: "> International rules for multiple primary cancers (ICD-0 third edition). Eur J Cancer Prev. 2005; 14(4):307–308. https://www.encr.eu/sites/default/files/pdf/MPrules_july2004.pdf [last access 29.6.2021]" added.

Changes made between version 1.2 and 1.3

Item / No / Page	Changes as of 01.01.2024
Title	V 1.2 to V 1.3 changed, date updated.
Imprint / p1	Weblinks and contact information updated.
Case definitions /p9	"No veto from patient" definition updated due to the amendment of Article 17, paragraph 1 of the Ordinance on the Registration of Cancer. Update of the listing of notifiable cancers due to amendment of Annex 1 of the Ordinance on the Registration of Cancer.
Place of birth / 1.10 / p24	Wording in the introduction in the Italian version updated. Weblinks in the section "References" in all languages updated.
Nationality / 1.11 / p25	Term 'nationality' in the German and in the Italian version changed to the correct and legally compliant official term. Weblinks in the section "References" in all languages updated.
Vital status / 1.13 / p27	Description of Code 2 in the Italian and French version according to the German version adjusted. Description of Code 3 to the status 'lost of follow-up' adjusted in all languages.
Date of informing the patient / 2.1 / p38	Sections "Rationale", "National Usage" and "Notes" adapted according to the amendment of Article 17, paragraph 1 of the Ordinance on the Registration of Cancer. The date informing the patient is forwarded to the NACR.
Date of incidence/ 2.3.1 / p40	Definition of the variable according to the updated recommendations of the ENCR adjusted. Text in the German, English and French versions taken over from the ENCR recommendation to coding incidence date (Italian version translated accordingly). Weblinks in the section "References" in all languages updated. "Notes* deleted because of new recommendation of the ENCR for urothelial tumours.
Most valid basis of diagnosis / 2.7 / p46	Variable adapted due to the updated ENCR recommendations in all language versions in the "Definition" and "Rationale" section. Text in the German, English, and French versions taken from the ENCR recommendation on diagnosis (Italian version translated accordingly). Weblinks in the section "References" in all languages updated.
Diagnostic method(s) used / 2.8 / p48	Sections "Rationale" and "Notes" adjusted due to ENCR's updated recommendations on the variable in all language versions.

END